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## Phenomenology of hoarding—What is hoarded by individuals with hoarding disorder?

Christopher Mogan <sup>a,\*</sup>, Michael Kyrios <sup>b</sup>, Isaac Schweitzer <sup>c</sup>, Keong Yap <sup>d</sup>, Richard Moulding <sup>b</sup>

- <sup>a</sup> University of Melbourne, Australia
- <sup>b</sup> Swinburne University of Technology, Australia
- <sup>c</sup> University of Melbourne and The Melbourne Clinic Professorial Unit, Australia
- <sup>d</sup> RMIT University, Australia

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#### ABSTRACT

Hoarding disorder is an under-recognized yet complex and pervasive psychological problem that dominates an individual's time, living spaces, relationships and safety. Hoarding behaviours have been associated with a number of disorders, including Obsessive-Compulsive Disorder (OCD), but as of yet, there has not been a systematic investigation of the presentation of hoarding phenomena across disorders. Simply—what do individuals with hoarding actually hoard, and does that differ from objects kept by people without hoarding? An understanding of the differential presentation of hoarding phenomena could help clarify the clinical status of hoarding disorder, which is currently under review. This study examined hoarding phenomena in 109 participants from five cohorts (individuals who hoard with and without comorbid OCD, individuals with OCD without hoarding, individuals with other Anxiety Disorders and non-clinical controls). The results supported the presence of hoarding symptoms across clinical and non-clinical cohorts, but some differences were apparent. In particular, individuals with hoarding disorder were far more likely than controls to collect idiosyncratic objects, some with deeply personal connections. Implications are discussed.

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#### 1. Introduction

Hoarding things is a normal human behaviour that arises from various symbolic, instrumental and artistic links which underpin the relationships humans form with objects (Nordsletten & Mataix-Cols, 2012). There is a growing awareness of a "disordered" type of hoarding, where the keeping of things is so pervasive that it dominates the person's life—their space and time, personal and social functioning. While the early papers on such hoarding were largely descriptive accounts that linked hoarding with severe and unusual presentations of OCD (Greenberg, 1987; Fitzgerald, 1997), more recent research has examined hoarding as a phenomenon in its own right, as distinct from OCD (e.g., see Mataix-Cols et al., 2010).

Reflecting this historical emphasis, there is a lack of clarity regarding hoarding in DSM-IV-TR (American Psychiatric Association, 2000), with hoarding appearing only as a symptom of Obsessive Compulsive Personality Disorder. This belies the seriousness of hoarding as a clinical problem, at least as damaging as the

other more recognized OCD-related symptoms (Steketee & Pruyn. 1998), particularly where hoarding and clutter have been known to lead to severe life-limiting injury from falls and fire-related injury, and even the death of sufferers (Lucini, Monk, & Szlatenyi, 2009). In an online survey of 864 individuals with compulsive hoarding, Tolin and colleagues (2008) concluded that hoarding disorder represents a profound public health burden, with work impairment similar to psychotic disorders, and greater work impairment than individuals with other anxiety, mood and substance abuse disorders. They also found that participants with hoarding disorder showed a high degree of a broad range of chronic and severe medical concerns, and had a five-fold higher rate of mental health service utilization. Eight to 12% had been evicted or threatened with eviction, while 0.1-3.0% had a child or elder removed from the home (Tolin, Frost, Steketee, Gray, & Fitch, 2008). There is a DSM-5 working party paper reviewing hoarding in order to give clinicians clearer clinical guidelines (Mataix-Cols et al., 2010), including questions of differential criteria and classification. Answers to these questions require research into the phenomenon of hoarding and any differences between individuals who hoard and those with OCD.

Phenomenological differences between hoarding disorder and OCD have traditionally been considered by examining differences in the clinical presentation or symptom profiles of individuals.

<sup>\*</sup> Correspondence to: The Anxiety Clinic, TMC 6, 140 Church Street Richmond, Victoria 3122, Australia. Tel.: +61 3 9420 1424; fax: +61 3 9421 0077. E-mail address: mogan@theanxietyclinic.com (C. Mogan).

For instance, individuals who hoard frequently do not view their behaviour as unusual and exhibit less insight into their behaviour than do those with other OCD symptoms (Black et al., 1988; Frost & Gross, 1993; Frost, Krause, & Steketee, 1996; Tolin, Fitch, Frost, & Steketee, 2010). As such, their thoughts regarding their possessions may be better described as "preoccupations", in contrast to the inherently distressing obsessive thoughts that occur in OCD (Rachman, Elliott, Shafran, & Radomsky, 2009). Hoarding-related thoughts have been noted to be "neither intrusive, nor unwanted, and certainly are not repugnant" (Rachman et al., 2009, p. 521). Furthermore, individuals who hoard do not have to perform a ritual in response to their thoughts (Mataix-Cols et al., 2010). Adding credence to such distinctions, individuals with hoarding often do not display any other OCD-symptoms (for review, see Mataix-Cols et al., 2010), and have a lower rate of comorbid OCD (18%) compared to depression, GAD and social anxiety (Frost, Steketee, & Tolin, 2011).

The present study aimed to explore another potential difference in the phenomenology of hoarding—specifically by systematically addressing the issue of what do individuals who hoard actually keep, and is this different from collecting behaviour in people without hoarding disorder? In addition to aetiological and diagnostic implications, a better understanding of the types of items saved between groups would help guide clinicians in the assessment and treatment of hoarding disorder with and without OCD. The only previous study to examine this issue found that individuals with Hoarding with and without OCD collected similar things, with the exception of letters, receipts, bills, old medication, and bizarre objects (all higher in individuals with OCD; Pertusa et al., 2008). The most kept items in both groups were old clothes, magazines, CDs, letters, and pens. To extend this analysis, we examined similarities and differences in hoarding phenomenology across four clinical groups-individuals with hoarding disorder with and without comorbid OCD; individuals with OCD without hoarding; individuals with other Anxiety Disorders and a community control group. This study included examining what objects individuals saved, and whether individuals who hoard saved different items from the other groups. It was hypothesized that the range of objects saved by the hoarding groups would differentiate individuals with hoarding from non-hoarding clinical and community control groups. However, consistent with Pertusa et al., we expected to find no significant difference between hoardings with and without OCD on items saved.

#### 2. Method

#### 2.1 Participants

A total of 89 clinical participants and 20 community controls volunteered for the study. Clinical participants were patients from University of Melbourne's Professorial and Psychology Clinics, members of community-based OCD support groups, or patients who found out about the study from other clinical referrals and general media publicity. The Research protocol was approved by the Research and Ethics Committee of the University of Melbourne. Participants were screened to exclude those with psychosis, dementia and related disorders. The age range of participants was 18-65 years. Five participants were not included in the study because the questionnaire data was incomplete. The Anxiety Disorders Interview Schedule for DSM-IV (ADIS-IV; Brown, Di Nardo, & Barlow, 1994) administered by clinical and provisional psychologists under supervision to verify diagnosis. As the ADIS-IV did not contain items for hoarding disorder, participants were assessed using an expanded version of the Hoarding Rating Scale-Interview (HRS-I; Tolin, Frost, & Steketee, 2010). Five groups participated: Group 1 consisted individuals diagnosed with hoarding disorder with comorbid OCD (HO, n=23); Group 2 consisted individuals with hoarding disorder without OCD (H, n=26); Group 3 comprised participants diagnosed with OCD but no hoarding (O, n=20); Group 4 comprised participants who fulfilled the DSM-IV criteria for Panic or Social Anxiety but not OCD (A, n=20); Group 5 was a community control group, matched with the hoarding cohort for age, gender and level of education, with no DSM-IV diagnosis nor a psychiatric history as determined by screening interviews (C, n=20).

#### 2.2 Procedure

Participants made contact with the research team via the telephone, mail or email to indicate their interest in participating. They were then contacted by the research team who arranged an interview. Each participant was provided with an information pack comprising: (1) a description of the study, a consent form, and detailed explanatory material on the study written in plain English to ensure adequate comprehension and clarity; and (2) two separate batches of questionnaires with replied paid envelopes. Other measures of cognitive, affective, and developmental factors were also administered to participants. These measures pertained to different research questions and results were reported elsewhere (Mogan, 2007).

Following informed consent, clinical interviews were conducted by the research team using the ADIS-IV, whether face-to-face for metropolitan-based enquirers or by telephone for rural or interstate respondents. Site visits were conducted if possible and photographs and third party reports obtained to confirm severity of hoarding. Participants were screened to exclude those with psychosis, dementia and related disorders. Each person was assigned a number to ensure confidentiality, anonymity and accurate matching of data sets. Demographic variables including age, gender, marital status, income, and education were collected across the five groups. Objects that were most saved and the symptomatic features of the five different groups were measured. With respect to the groups with hoarding behaviour, information about comorbidities and potential hazards noted were also collected.

#### 2.3 Materials

The Anxiety Disorders Interview Schedule for DSM-IV (ADIS-IV; Adult Version: Brown et al., 1994) is a semi-structured interview screening of DSM-IV criteria for anxiety and related disorders.

The Savings Inventory—Revised (SIR; Frost, Steketee, & Grisham, 2004) is a 23 item self-report scale designed to measure the major features of hoarding disorder (Frost & Hartl, 1996) Items were scored on a 5-point Likert scale. In this study, excellent internal consistency was shown with a Cronbach's  $\alpha$  of .98.

The Savings List (Kyrios, 2002) is a descriptive list of 82 common objects saved or hoarded as a systematic guide to the type of things being collected by clinical and non-clinical groups that has been used in a number of studies (Wincze, 2001; Kyrios, 2002; Novara, unpublished). Participants were asked to indicate the extent to which they saved each items on a 7-point Likert scale from 1 (Not at all—I only save what I need or use) to 7 (Very much—I save an excessive amount. Far more than I will ever use). Space was provided for participants to include and rate additional items. In this study, two methods of scoring were used: (1) the sum total of all 82 items, and (2) the number of items saved at the upper end of the Likert scale (scores 5–7).

The Hoarding Rating Scale-Self Report (HRS-SR; Tolin et al., 2008) consisted of five self-report diagnostic criteria proposed for

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