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Research report

Caregiver burden, family accommodation, health, and well-being in relatives of individuals with hoarding disorder



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ABSTRACT

Background: Hoarding Disorder (HD), a new diagnostic entity in DSM-5, is associated with substantial functional impairment and family frustration but data from well-characterized samples is lacking.

Method: Participants were 37 individuals meeting DSM-5 criteria for HD, 55 relatives of individuals meeting criteria for HD, and comparison groups of 51 self-identified collectors and 25 relatives of collectors. All participants completed a clinician-administered diagnostic interview for HD and an online battery of standardized measures of health, well-being, and impairment.

Results: Substantial functional impairment was found for both HD individuals and their relatives. HD relatives reported significantly greater carer burden and accommodation of hoarding behaviors than relatives of collectors. Perceived level of squalor, co-habiting with, and increasing age of the HD individual were significant predictors of carer burden and functional impairment in the relatives.

Limitations: The use of self-identified HD individuals may have produced a bias towards participants with relatively good insight. Subjective biases in self-reported symptoms cannot be ruled out, although the use of informant-report data provided some independent validation.

Conclusions: HD is associated with substantial functional impairment for both sufferers and their relatives. The level of carer burden experienced by HD relatives was comparable to or greater than that reported in the literature by relatives of individuals with dementia. The findings indicate that relatives of individuals with HD may benefit from increased support and suggest that it may be beneficial to involve family members in the treatment of HD.

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1. Introduction

Hoarding Disorder (HD) is a psychiatric disorder characterized by persistent difficulties discarding possessions, leading to the accumulation of clutter that substantially restricts the use of active living areas, and associated clinically significant distress or functional impairment; these symptoms are not attributable to other medical or psychiatric conditions (American Psychiatric Association, 2013).

Individuals who experience hoarding difficulties are known to be impaired in several areas of everyday functioning such as cooking, washing up, paying bills, and performing well at work (Frost et al., 2013; Kim et al., 2001). As a result of their particular challenges in maintaining a clean home, individuals with hoarding

difficulties have also been found to be at increased risk for chronic medical conditions and higher rates of health care utilization compared to non-hoarding individuals (Tolin et al., 2008). A study of individuals with Obsessive-Compulsive Disorder (OCD) treated in an intensive multimodal program found that those with hoarding symptoms and OCD reported lower quality of life than non-hoarding OCD individuals, particularly on domains assessing safety and living arrangements (Saxena et al., 2011).

In addition to the impact experienced directly by those who hoard, research has suggested that those caring for, or living with, a hoarding individual also experience repercussions of hoarding (see e.g., Tolin et al., 2008). Frost et al. (2000) for example, highlighted that hoarding can lead to violations of local health, housing and sanitation laws, which have the potential to impact on family, carers, neighbors, and the wider community. Lower rates of marriage and higher rates of divorce have also been reported for those who hoard in both postal surveys of self-identified individuals with hoarding (Steketee et al., 2003) and individuals meeting diagnostic criteria for HD who were visited at

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home (Nordsletten et al., 2013a), suggesting problems in domestic relationships. In an internet-based survey, Tolin et al. (2008) found higher rates of frustration among the family members of those who hoard compared to the families of those seeking OCD treatment. Furthermore, in that study, the relatives' perceptions of poorer insight, increased hoarding severity, and clutter in their childhood environment were associated with increased frustration. However, the question of whether an individual's hoarding severity and insight are related to different types of family impacts – for instance, health repercussions versus impact on daily functioning – has not yet been explored. In a qualitative investigation in which partners and carers of individuals with hoarding were interviewed in their family homes, Wilbram et al. (2008) identified a range of ways in which carers support individuals with hoarding in completing basic activities that would otherwise be neglected such as self-care and managing finances. This work also described significant accommodation of hoarding behaviors by carers, who would not only avoid disturbing clutter in order to reduce the hoarding individual's distress, but also sometimes physically accommodated clutter in their own homes when there is insufficient space in the hoarder's residence (Wilbram et al., 2008).

Taken together, this preliminary literature clearly suggests that hoarding may adversely impact both the sufferers and those around them, though much of the evidence is based on postal or web-based surveys of self-identified individuals or relatives of individuals with hoarding difficulties. As HD has only recently been recognized as a disorder in its own right, few of the above-mentioned studies used DSM-5 diagnostic criteria to select participants. This is critical as some of the reported impacts may in fact be due to other medical or psychiatric conditions that are known to result in the pathological accumulation of objects, rather than HD itself.

The present study aimed to further elucidate the nature and extent of impairment associated with strictly diagnosed HD, both for sufferers themselves and their relatives, as compared with a control group of healthy collectors and their relatives. Prior work has highlighted the similarities between hoarding and collecting behavior, with participants in both activities showing an interest in the accumulation of possessions and a strong emotional attachment to these items (e.g., Nordsletten and Mataix-Cols, 2012; Nordsletten et al., 2013a). As such, collectors permit us to examine whether the features under investigation (e.g., family burden) are specific to HD, or whether they are a product, more generally, of environments that place an emphasis on the acquisition of, or affection for, objects.

In particular, the present study aimed to quantify and directly compare the level of functional impairment, health and well-being for individuals with HD compared to HD relatives and the non-clinical comparison groups using standardized measures. Family accommodation was also identified as an area of interest since this has not been systematically examined in previous research. It was predicted that individuals with HD and HD relatives would report greater functional impairment and poorer health and well-being compared to collectors and their relatives. It was also predicted that HD relatives would report greater carer burden, accommodation, and impact compared to relatives of collectors.

2. Methods

2.1. Participants and procedures

Individuals with hoarding difficulties were recruited primarily from London-based support groups. Collectors were recruited primarily via online advertisements on relevant forums and

popular social networks. Additional participants were recruited through existing contacts with hoarding and collecting individuals, some of whom had engaged previously with our research at the Institute of Psychiatry. The sample included 37 individuals meeting DSM-5 criteria for HD, 55 relatives of individuals meeting criteria for HD (according to the informant-report), 51 self-identified collectors, and 25 relatives of self-identified collectors. In the HD group, 19 participants (51%) had a relative who also participated in the study as part of the HD relatives group (one HD participant had two relatives who participated) and 18 (49%) took part in the study without a relative. In the collector group, 24 participants (47%) had a relative who also participated in the study as a relative of a collector and 27 (53%) took part in the study without a relative. The remainder of the two relative groups consisted of a further 35 (64%) HD relatives and 1 (4%) relative of a collector who took part in the study without an index hoarding/collecting relative.

The final sample were part of a larger number of individuals (HD group $N=41$, HD relatives $N=60$, collector group $N=55$, relatives of collectors $N=26$) who were interviewed, some of whom were excluded from the final analyses because they did not meet our inclusion criteria. For the HD group and HD relatives, the main inclusion criterion was that the index individual with hoarding met diagnostic criteria for HD. For the collecting group and relatives of collectors, the main inclusion criterion was that the index collecting individual had at least one collection of items of a similar type or theme, and the main exclusion criterion was the index collecting individual meeting criteria for HD. Five self-identified individuals with hoarding were excluded due to clutter below the clinical cut-off (Criterion C) and two because hoarding was found to be due to OCD concerns (Criterion F). Three participants who self-identified as collectors in fact met diagnostic criteria for HD and were therefore included in the HD sample. One participant self-identified as a collector but when interviewed reported that he did not currently have a specific collection. Two relatives of individuals with hoarding were excluded because their relatives with hoarding did not meet Criterion C, and three because their relatives with hoarding did not meet Criterion F (2 had hoarding linked to OCD concerns and one described clutter due to Attention Deficit Hyperactive Disorder). One relative of a collector was excluded because their relative did not have a clearly defined collection.

After a brief screening to gauge potential suitability for the study, participants were interviewed over the telephone and administered the Structured Interview for Hoarding Disorder (SIHD; Nordsletten et al., 2013b), a semi-structured interview that assists in the diagnosis of HD according to DSM-5 diagnostic criteria (American Psychiatric Association, 2013). The HD and collector groups reported on their own hoarding/collecting behaviors while the relatives were asked to report on the behavior of the individual with hoarding/collecting. Participants also completed a series of online questionnaires (see Section 2.2) accessed through a website set up for the study.

Following completion of the diagnostic interviews and questionnaires, the presence of HD was determined through the best estimate diagnosis procedure, as described by Leckman et al. (1982). In the present study, a group of four HD researchers met regularly and reviewed all available information for each participant, including transcripts of the phone interviews and ratings on the various hoarding severity measures. For hoarding/collecting participants whose relatives also took part in the study, informant-ratings as well as self-ratings were reviewed in the consensus meetings. Participants were provided with a small gift voucher (£5) as a token of appreciation for their participation.

The study was reviewed and approved by the King's College Research Ethics Committee and all participants gave informed consent in accordance with this.

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