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Family and social functioning in adults with hoarding disorder

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Abstract

Hoarding is associated with problems engaging in social activities, lower social support, increased isolation and poses substantial challenges to family functioning. The aim of this investigation was to explore the relationship between hoarding severity and family and social functioning variables in 60 treatment-seeking adults with hoarding disorder (HD). Participants completed a battery of self-report measures during a baseline assessment completed prior to treatment. Forty-seven percent of participants reported they live alone. Forty-eight percent of participants reported that family and friends never visit them in their home, and 33% indicated they never had visitors to their home, not even service workers or repair people. Twelve percent of participants indicated they never visit with family or friends outside of their home; however, 55% of participants endorsed phoning family or friends more than 9 times each month. Increased clutter and hoarding severity was associated with a lower frequency of family and friends visiting in the home. Family competence and conflict were both positively associated with hoarding severity. Our results shed light on family and social impairment in HD and their relationship with symptom severity; however, additional research should examine social dysfunction among non-treatment-seeking individuals who may be more impaired or isolated.

Introduction

Hoarding disorder (HD) is a debilitating health problem involving persistent difficulties with discarding and/or parting with possessions, regardless of their value, and the accumulation of a large number of possessions that clutter living areas (American Psychiatric Association, 2013). Prevalence rates for HD range from 2% to 6% (Postlethwaite et al., 2019), with symptoms typically emerging before 20 years of age and progressing over the lifespan (Dozier et al., 2016; Cath et al., 2017).

Individuals with hoarding symptoms have more psychosocial impairment and greater interpersonal difficulties than individuals without hoarding symptoms, including in comparison to those with other psychiatric conditions (Ayers et al., 2010; Nedelisky & Steele, 2009). Hoarding is also associated with problems engaging in social activities (Diefenbach et al., 2013), lower social support (Medard & Kellet, 2014) and increased social isolation (Steketee et al., 2000). The link between hoarding and social involvement may be due to excessive clutter (Saxena et al., 2002) or reduced emotional involvement with other individuals (Nedelisky & Steele, 2009).

Similarly, HD interferes with family functioning (Drury et al., 2014). Hoarding can lead to sanitation, health and housing violations which may potentially impact the safety of family members (Frost et al., 2000). HD relatives have stated that they experience a loss of 'normal' family life due to the inability to use rooms in the home and have others visit (Wilbram et al., 2008). Relatives of hoarding patients report lower health and emotional well-being, as well as increased pain, when compared to relatives of collectors (Drury et al., 2014). Clutter and hoarding-related impairments may be exacerbated by the presence of multiple family members with HD in the home, as nearly half of individuals with HD report having a first-degree relative with hoarding tendencies (Ayers & Dozier, 2015).

Family members of HD patients report high rates of familial frustration and hostility (Wilbram et al., 2008), which may be amplified when those with HD display poor insight (Drury et al., 2014). Family hostility, combined with poor interpersonal skills, often leads to increased alienation of the individual (Tolin et al., 2008) and ultimately the breaking up of families (Tompkins, 2011). Children living in an extremely cluttered environment have elevated levels of distress, and adult children of individuals with HD retrospectively report

decreased happiness during childhood (Tolin et al., 2008). Along with poor communication, impaired relationships and poor insight, a lack of understanding around HD, specifically by non-caretaking family members, can be a significant source of familial distress (Sampson et al., 2012).

To address gaps in the literature pertaining to hoarding and family functioning, the purpose of the current investigation was to explore the relationship between hoarding severity and family and social functioning variables in 60 treatment-seeking adults with HD. To this end, we aimed to characterise and examine the association of the number of family members living in the home, family functioning and social participation with hoarding severity. Our second aim was to compare hoarding severity and family/social functioning variables in those who reported hoarding symptoms onset early in life (i.e., before they were 20), versus those who reported a later onset.

Methods

Participants

This study utilised baseline data from 60 adults enrolled in group behavioural treatment for HD (Ayers et al., 2018). Participants were recruited from the community between March 2013 and May 2014 via flyers and clinician referrals. All procedures were reviewed and approved by the local institutional review board. All participants were assessed for DSM-5 criteria of HD during a clinical interview conducted during the baseline assessment administered in the clinic prior to enrolment in treatment. Thus, participants were required to report clinically significant hoarding symptoms, distress or impairment resulting from those symptoms, and to not have a medical or psychiatric disorder that better explained the hoarding symptoms. Participants were excluded if they were receiving concurrent psychotherapy, endorsed active suicidal ideation, a history of psychosis or if they were determined to be cognitively impaired on a screening measure.

Measures

Hoarding symptoms were assessed by the Saving Inventory-Revised (SI-R; Frost et al., 2004), a 23-item self-report measure that utilises a Likert-type scale rated 0–4. The SI-R includes three subscales for clutter, difficulty discarding and acquisition which are summed for a total score. The SI-R has demonstrated good internal consistency, retest reliability, discriminant and convergent validity (Frost et al., 2004). Reliability of the SI-R in the current sample was adequate $\alpha = 0.90$. The Clutter Image Rating Scale (CIR; Frost et al., 2008) was used to assess clutter volume in the home. Respondents rate the level of clutter in their living room, bedroom and kitchen by selecting the image (labelled 1–9) that most closely corresponds with their living space The CIR has demonstrated good retest reliability, internal consistency, convergent validity and excellent inter-observer agreement (Frost et al., 2008).

Ability to participate in social roles and activities was assessed with the PROMIS-43 Profile v2.1 (Hahn et al., 2014). Items are rated from 1 to 5 on a Likert-type scale, summed to create a total raw score and converted into T-scores. Higher scores represent greater ability to participate in social activities. Family functioning was assessed with the 36-item Self-report Family Inventory (SFI; Beavers et al., 1990). The SFI includes five subscales representing (1) overall family health/competence, (2) cohesion, (3) conflict, (4) leadership and (5) emotional expressiveness. Items are rated on a Likert-type scale from 1 (Yes: fits our family very well) to 5 (No: does not fit our family), with lower scores indicating better family functioning. The SFI has demonstrated good internal consistency, retest reliability and concurrent validity with other family measures (Beavers et al., 1990).

Participants completed a personal history questionnaire developed for the initial investigation (Ayers et al., 2018) that assessed who (if anyone) lives in their home with them, if there is a history of hoarding in their family and the frequency that they socialise with family and friends. Questions about socialisation and the number of family members living in the home were answered on a categorical scale ranging from 'Live alone' to '4 other people', and 'Never' to '9+ times per month', respectively. On a hoarding timeline (Grisham et al., 2006), participants indicated the presence and severity (mild, moderate or severe) of three core hoarding symptoms (i.e., saving, clutter and difficulty discarding) and their level of insight from 0 (no recognition) to 3 (substantial or complete recognition) during each decade of life (e.g., 0–10, 10–20, until 80+). Clinical onset of HD was established when participants rated two or more of the three core symptoms as mild or one symptom as moderate (Grisham et al., 2006).

Data analysis

All analyses were performed using SPSS Statistics Version 26 (IBM Corp, 2019). Zero-order correlations were conducted between hoarding severity on the SI-R and CIR, ability to participate in social roles and activities on the PROMIS-43 Profile v2.1, frequency of visitation and socialisation in and outside of the home and the SFI. We utilised independent samples *t*-tests to explore differences in hoarding severity and family/social functioning variables in those who reported clinical onset between the ages of 0 and 20, versus those who indicated clinical onset after 20 years of age.

Results

Descriptive statistics for demographic variables and hoarding severity and social and family functioning measures are presented in Tables 1–2. Participants' average reported ability to participate in social roles on the PROMIS-43 Profile v2.1 was consistent with the presence of mild social impairment (Hahn et al., 2014). The median age for clinical onset of hoarding symptoms was between 20 and 30 years, and the median age of onset for hoarding insight was one decade later, between 30 and 40. Overall, 45% of the sample endorsed clinical onset during the first two decades of life. The majority of participants (67%) reported having a first-degree relative with clutter and difficulties discarding. Twenty-three percent of participants indicated having a second-degree relative with clutter and difficulties discarding. Thirty-seven percent endorsed growing up in a home with substantial clutter.

Fifty-two percent of participants indicated they had children and 23% reported they had grandchildren. Forty-seven percent of participants reported they live alone. Forty-eight percent of participants reported that family and friends never visit them in their home, and 33% indicated they never had visitors to their home, not even service workers or repair people. Twelve percent of participants indicated they never visit with family or friends outside of their home; however, 55% of participants endorsed phoning family or friends more than 9 times each month.

On the SFI, family competence was significantly associated with hoarding symptoms on the CIR ($r = 0.298$, $p = 0.030$) and

Table 1. Demographic characteristics of 60 adults enrolled in group behavioural treatment for HD

		Mean	*SD*	Range
Age		58.73	10.09	29–85
Education		15.43	2.17	11–21
		N		%
Gender, % Women		44		73
Race	White	47		78
	Black	2		3
	Asian	4		7
	Hispanic	3		5
	Biracial	3		5
	Other	1		2
Marital status	Never married	19		32
	Married or living with partner	16		27
	Separated/divorced	22		37
	Widowed	2		3
Employment status	Retired	17		28
	Employed full- or part-time	28		50
	Unemployed	9		15
	Disabled	7		12
Number of other people in the home	Live alone	28		47
	One other person	15		25
	Two other people	8		13
	Three other people	2		3
	Four other people	2		3
Frequency of family/ friends as visitors	Never	29		48
	1–2 times per month	22		37
	3–5 times per month	2		3
	6–8 times per month	0		0
	9+ times per month	1		2
Frequency of socialisation outside of home	Never	7		12
	1–2 times per month	12		20
	3–5 times per month	13		22
	6–8 times per month	14		23
	9+ times per month	8		13
Frequency of socialisation by phone	Never	2		3
	1–2 times per month	5		8
	3–5 times per month	8		13
	6–8 times per month	4		7
	9+ times per month	33		55

Table 2. Descriptive statistics of 60 adults enrolled in group behavioural treatment for HD

		Mean	*SD*	Range
Saving Inventory-Revised	Total	57.92	12.49	36–89
	Difficulty discarding	19.08	3.96	10–28
	Acquisition	15.44	4.93	6–28
	Clutter	23.39	7.54	4–36
Clutter Image Rating		4.08	1.55	1–9
Ability to participate in social roles and activities*		40.61	7.64	26.7–57.5
Family health/competence		2.97	0.85	1–5
Family conflict		2.59	0.94	1–5
Family cohesion		3.31	0.74	1–5
Family expressiveness		2.61	1.04	1–5
Family leadership		2.87	0.86	1–5

*Assessed using the PROMIS-43 Profile v2.1. Presented as *T*-scores.

Table 3. Zero-order correlations among hoarding and family/social functioning variables

	Clutter Image Rating		Saving Inventory – Revised	
	R	*p*	*r*	*p*
Number of individuals in household	−0.167	0.223	0.005	0.972
Family/friends visit in home	−0.542	<0.001	−0.481	0.000
Family/friends visit outside home	−0.100	0.470	−0.042	0.763
Phone family/friends	−0.125	0.378	−0.119	0.400
Ability to participate in social roles and activities	−0.147	0.280	−0.388	0.003
Family health/competence	0.298	0.030	0.293	0.033
Family conflict	0.226	0.104	0.333	0.015
Family cohesion	0.253	0.067	0.218	0.117
Family expressiveness	0.247	0.074	0.237	0.088
Family leadership	−0.142	0.311	−0.115	0.413

SI-R ($r = 0.293$, $p = 0.033$) such that worse functioning, that is, higher SFI scores, was associated with greater symptom severity. Likewise, greater family conflict was associated with greater symptom severity on the SI-R ($r = 0.333$, $p = 0.015$). Lower incidence of family or friends visiting in the home was significantly associated with hoarding severity per the CIR ($r = -0.542$, $p < 0.001$) and SI-R ($r = -0.481$, $p < 0.0010$). Lower scores on the PROMIS-43 ability to participate in social roles was significantly associated with greater hoarding severity on the SI-R ($r = -0.388$, $p = 0.003$). No other social or family functioning measures were significantly

Table 4. Independent samples t-tests comparing hoarding and family/social functioning variables in those whose symptoms onset before versus after age 20.

		Early onset		Adult onset				
		n	Mean (*SD*)	*n*	Mean (*SD*)	*t* (df)	*p*	95% CI
Saving Inventory-Revised	Total	27	60.89 (13.48)	29	55.76 (11.41)	−1.54 (54)	0.129	−11.8–1.5
	Difficulty discarding	27	20.19 (4.12)	29	18.00 (3.64)	−2.11 (54)	**0.040***	−4.3–−0.11
	Acquisition	27	17.26 (5.53)	29	13.76 (3.87)	−2.76 (54)	**0.008****	−6.0–−0.96
	Clutter	27	23.44 (7.01)	29	24.00 (8.03)	0.28 (54)	0.784	−3.5–4.6
Clutter Image Rating		27	4.07 (1.40)	30	4.11 (1.65)	0.09 (55)	0.928	−0.78–0.85
Ability to participate in social roles and activities		26	39.35 (7.28)	28	41.01 (7.68)	0.82 (52)	0.417	−2.4–5.8
Family health/competence		25	2.93 (.81)	26	3.06 (0.90)	0.53 (49)	0.602	−0.36–0.61
Family conflict		25	2.71 (0.87)	26	2.58 (0.97)	−0.53 (49)	0.600	−0.66–0.38
Family cohesion		25	3.28 (0.68)	26	3.35 (0.83)	0.35 (49)	0.730	−0.35–0.50
Family expressiveness		25	2.62 (1.15)	26	2.65 (0.98)	0.07 (49)	0.941	−0.58–0.62
Family leadership		25	2.64 (0.79)	26	3.09 (0.91)	1.90 (49)	0.066	−0.03–0.93

associated with hoarding symptom severity (see Table 3). There was a significant difference between hoarding onset groups on the acquisition ($t(54) = -2.11$, $p = 0.04$, 95% CI: −4.26–−0.11) and difficulty discarding ($t(54) = -2.76$, $p = 0.008$, 95% CI: −6.04–−0.96) subscales of the SI-R, such that earlier onset was associated with increased hoarding symptom severity. Otherwise, there were no significant differences between groups (see Table 4).

Discussion

While other studies have sought to understand familial relationships in HD samples (Steketee et al., 2015) and evaluate parent–adult offspring perspectives (Park et al., 2014), this is one of the first studies to explore family characteristics and functioning, social participation and their association with hoarding severity. Worse overall family functioning was associated with increased hoarding severity on measures of both clutter volume and specific hoarding symptoms (i.e., difficulty discarding and acquiring). These findings are consistent with prior work that found family functioning mediated the association between hoarding severity and parent–offspring relationship (Park et al., 2014). Participants' perceived impaired ability to actively socialise with their family and greater family conflict were associated with greater symptom severity. Given that avoidance is a core feature of HD and may generalise to other areas of life, individuals with HD may cope with familial conflicts by avoiding these interactions.

Families can be instrumental in supporting individuals with psychiatric illness or harmful (Steketee, 1993; Thompson-Hollands et al., 2014). Research suggests that families can be unsupportive of their relatives with HD, and that interventions targeting families can improve family members' well-being and knowledge of HD (Chasson et al., 2014) but do not necessarily reduce hoarding symptoms (Thompson et al., 2017). Our results further demonstrate the association between family dysfunction and hoarding severity. Specifically, poor family competence (i.e., cohesion, organisation, communication and cooperative problem-solving) and greater family conflict were associated with more severe clutter volume and hoarding symptoms. Additional research examining the specifics factors that contribute to poor family competence and greater conflict may help clarify which elements of family functioning reinforce or mitigate hoarding behaviours.

We did not find any significant association between the number of family members living in the home and symptom severity; however, increased clutter and hoarding severity was associated with a lower frequency of family and friends visiting in the home. Few participants in this sample (15%) reported at least three or more visits to their home by family and friends each month, nearly half indicated they never had visitors to their home, and an additional 38% reported only one or two visits from family and friends each month. These results are consistent with the level of anger and frustration family members report feeling towards their loved one with HD (Park et al., 2014). Participants reported having some in-person contact with family and friends outside of their own home and relatively frequent contact by telephone, which supports that teletherapy may be a feasible option for HD treatment.

This study is not without limitations that impact the generalisability of our results. The sample was relatively small and consisted primarily of white females, who were highly educated and seeking treatment for HD. Moreover, we utilised a cross-sectional design and collected self-report data without supporting collateral information from family members. The available measures used in the study were not exhaustive of family and social functioning yet provide some additional information on these areas among individuals with HD. The SFI was developed using the Beavers Systems Model of family functioning. Future studies may consider including measures based on other family functioning models, such as the Family Assessment Device (Epstein et al., 1983), which is based on the McMaster Model of Family Functioning, and the Family Adaptability and Cohesion Evaluation Scales (Olson, 2011), which is based on the Circumplex Model of Marital and Family Systems.

Our results shed light on family and social impairment in HD and their relationship with symptom severity; however, additional research should examine social dysfunction among non-treatment-seeking individuals who may be more impaired or isolated socially. Longitudinal research may clarify the temporal relationship between family/social dysfunction and hoarding

symptoms as well as examine how social and familial supports can be leveraged to improve treatment outcomes for those with HD. While difficulties discarding and acquiring are often the focus of HD treatment, other areas of functioning may require clinical attention.

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