Short communication

Quality of life in patients with hoarding disorder

David F. Tolin\textsuperscript{a,b}, Akanksha Das\textsuperscript{a}, Lauren S. Hallion\textsuperscript{b,c}, Hannah C. Levy\textsuperscript{a}, Bethany M. Wootton\textsuperscript{a,d}, Michael C. Stevens\textsuperscript{a,b}

\textsuperscript{a} Institute of Living, Hartford, CT, United States
\textsuperscript{b} Yale University School of Medicine, New Haven, CT, United States
\textsuperscript{c} University of Pittsburgh, Pittsburgh, PA, United States
\textsuperscript{d} University of Technology Sydney, Sydney, Australia

\textbf{ABSTRACT}

The aim of this study was to investigate health-related quality of life (QoL) in patients with hoarding disorder (HD). Fifty-four patients with a primary diagnosis of HD, and 24 age- and sex-matched healthy control (HC) participants, completed a battery of questionnaires including the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), Saving Inventory-Revised, and Depression, Anxiety, Stress Scales. Compared to HC participants, those with HD reported poorer health-related QoL across all domains of the SF-36. When controlling for comorbid affective symptoms, HD participants scored lower than did HC participants in the QoL domains of social functioning, emotional well-being, role limitations due to emotional problems, vitality, and general health. HD symptom severity predicted, beyond the effects of affective symptoms, lower QoL in social functioning, emotional well-being, role limitations due to emotional problems, vitality, and general health.

1. Introduction

Hoarding disorder (HD), a newly recognized diagnosis in the \textit{Diagnostic and Statistical Manual of Mental Disorders, 5\textsuperscript{th} Edition} (DSM-5) (American Psychiatric Association, 2013), is defined as a persistent inability to discard possessions, often accompanied by excessive acquiring, resulting in severe clutter that precludes normal use of living spaces (Frost & Gross, 1993; Frost & Hartl, 1996). Though hoarding was initially conceptualized as a subtype of obsessive-compulsive disorder (OCD), and was initially studied in the context of OCD, a growing body of research points to distinctions between HD and OCD (Abramowitz, Wheaton, & Storch, 2008; Grisham, Brown, Liverant, & Campbell-Sills, 2005; Pertusa et al., 2010), leading to its inclusion as a unique diagnosis in DSM-5.

Hoarding is associated with high levels of functional impairment. Among OCD patients, those presenting with hoarding symptoms reported higher levels of disability in a range of daily activities than did those with OCD without hoarding (Lochner et al., 2005). Similarly, individuals with HD report elevated levels of disability compared to non-pathological “collectors” (Nordsletten, Fernandez de la Cruz, Billotti, & Mataix-Cols, 2013). In addition to functional impairment, HD may also adversely affect health-related quality of life (QOL) across a variety of physical and mental health domains. Current models of HD suggest that this condition is maintained by factors such as decision-making impairment, deficits in basic cognitive function, emotional dysregulation and intolerance, and behavioral avoidance (e.g., Steketee & Frost, 2003; Timpano, Shaw, Cougle, & Fitch, 2014; Woody, Killman-McFarlane, & Welsted, 2014). It might be expected that these underlying impairments may also interfere with accomplishing other desired goals. Additionally, the resulting clutter may even physically interfere with carrying out other activities due to unusable living spaces, or lead to avoidance of social contact in the home. Despite these intuitive theoretical links between HD and QoL, few studies have examined QoL in individuals with hoarding symptoms (Ong, Pang, Sagayadevan, Chong, & Subramaniam, 2015). In patients with OCD (N = 65) (Fontenelle et al., 2010), a combination of hoarding, depression, and employment status predicted 62% of the variance in the social functioning dimension of the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) (Ware, 1993). Another study of OCD patients (N = 151) (Albert, Maina, Bogetto, Chiarle, & Mataix-Cols, 2010), however, found no significant relationship between hoarding symptoms and SF-36 scores. One study of HD (which predated the DSM-5 diagnosis but used similar criteria) (Saxena et al., 2011) found that HD patients (N = 34) reported significantly lower QoL across multiple domains than did non-hoarding OCD patients (N = 137) on the Lehman Quality of Life interview (Lehman, 1988). The HD group was significantly older than the OCD group, however, which could have impacted results. Importantly, the two groups did not differ significantly.

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E-mail address: david.tolin@hhchealth.org (D.F. Tolin).

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in terms of depression or anxiety, suggesting a unique relationship between hoarding and QoL.

The first aim of this study was to replicate prior findings (Saxena et al., 2011) of low QoL in patients with DSM-5 HD. The study builds on previous findings by using formal DSM-5 HD criteria, a larger sample of adults with HD (N = 54), and an age- and sex-matched healthy control (HC) group (N = 24), and using the SF-36, which provides a more thorough assessment of health-related QoL than has been obtained in previous studies. It was predicted that HD patients would report significantly lower QoL across all domains than would HCs. A second aim was to examine the relationship among HD symptoms, depression, and QoL. It was predicted that QoL would be related to the severity of various HD symptoms, and that these relationships would remain significant even when controlling for depression severity.

2. Methods

2.1. Participants

Fifty-four patients meeting DSM-5 (American Psychiatric Association, 2013) criteria for HD were sampled as part of a larger protocol investigating changes in neural activity during cognitive-behavioral therapy for HD. Participants were included if they met criteria for a primary diagnosis of HD of at least moderate severity, were aged 20–65, and were free of serious mental illness (e.g., schizophrenia) or current substance abuse. Patients could have other comorbid diagnoses (e.g., OCD, depressive disorders) as long as the HD diagnosis was primary. Participants were also required to meet certain requirements for functional magnetic resonance imaging (fMRI), such as absence of metal in the body. To minimize confounds for the clinical trial, patients had to be off psychiatric medications or on a stable dose of medications for at least 8 weeks. Twenty-four healthy control (HC) participants were also recruited, with no current or past psychiatric diagnosis or treatment. HC participants were age- and gender-matched to the HD sample by recruiting HC participants in batches and attempting to match the distribution of the HD sample.

2.2. Measures

The Diagnostic Interview for Anxiety, Mood, and Obsessive-Compulsive and Related Neuropsychiatric Disorders (DIAMOND) (Tolin, Gilliam, Wootton, et al., 2018) was used to assess DSM-5 diagnoses. The DIAMOND HD diagnosis shows excellent inter-rater reliability, very good test-retest reliability, and strong convergent validity (Tolin, Gilliam, Wootton, et al., 2018). The Clinician’s Global Impression-Hoarding Disorder (CGI-HD) (Tolin, Gilliam, Davis, et al., 2018) was used to identify illness of at least moderate severity. The CGI-HD rates symptom severity on a 1–7 scale and shows good inter-rater and test-retest reliability (Tolin, Gilliam, Davis, et al., 2018).

The Saving Inventory-Revised (SI-R) (Frost, Steketee, & Grisham, 2004) was used to measure severity of HD symptoms. This self-report measure yields a total score as well as three subscales: Clutter (α = 0.98 in the present sample), Saving (α = 0.96 in the present sample), and Acquiring (α = 0.94 in the present sample). The SI-R shows good reliability, as well as convergent and criterion-related validity (Frost et al., 2004). The Hoarding Rating Scale-Interview (HRS-I) (Tolin, Frost, & Steketee, 2010) was also included for sample description. This clinician-rated interview has good convergent and criterion-related validity (Tolin et al., 2010; Tolin, Gilliam, Davis, et al., 2018). α was 0.97 in the present sample. The Depression Anxiety Stress Scales (DASS) (Lovibond & Lovibond, 1995) was used to measure comorbid affective symptoms. This self-report measure is comprised of three subscales which show high internal consistency and good discriminant and divergent validity (Lovibond & Lovibond, 1995). In the present study, the depression (DASS-D, α = 0.93), anxiety (DASS-A, α = 0.86) and stress (DASS-S, α = 0.80) subscales showed excellent internal consistency.

Health-related QoL was measured using the MOS 36-Item Short Form Survey (SF-36) (Ware, 1993), a measure of 8 domains of health-related quality of life (i.e., physical functioning, social functioning, emotional well-being, role limitations due to physical health, role limitations due to emotional problems, vitality, pain, and general health). In the present study, reliability on the 8 domains ranged from low to high (physical functioning, α = 0.91; social functioning, α = 0.75; emotional well-being, α = 0.76; role limitations due to physical health, α = 0.83; role limitations due to emotional problems, α = 0.63; vitality, α = 0.80; pain, α = 0.49; and general health, α = 0.85). Scores range from 0 to 100, with higher scores indicating better QoL.

2.3. Procedure

Other data from this sample have been reported elsewhere (e.g., Tolin, Hallion, et al., 2018). The HD group (recruited from the clinic flow, newspaper advertisements, community lectures, and flyers in the community) was seeking treatment as part of a clinical trial. The HC group was recruited via newspaper advertisements and flyers in the community. HD participants received $50 for completing the assessment, whereas HC participants received $125. After providing informed consent, participants met with a doctoral-level psychologist or supervised postdoctoral fellow who administered the DIAMOND and HRS-I. They then completed a battery of self-report measures, including the SI-R, DASS, and SF-36. The study was approved by the hospital’s Institutional Review Board.

2.4. Data analytic strategy

SF-36 scores were compared for HD and HC participants using a 2 (group: HD, HC) X 8 (SF-36 subscale) mixed-factor GLM with subscale as the repeated measure. Effect sizes (partial eta-squared, ηp²) were calculated. A similar analysis was conducted using the three DASS subscales (depression, anxiety, stress) as covariates. To examine the relationship between HD symptom severity and quality of life, we conducted a series of linear regressions with each of the SF-36 subscales as the dependent measures. In the first block, we entered the three DASS subscales (depression, anxiety, stress) as predictor variables. In the second block we entered SI-R total score. These regressions were calculated for the total sample and for the HD group separately. To control for multiple comparisons, we used a Bonferroni correction (total number of comparisons = 8, α = 0.006).

3. Results

3.1. Sample description

As shown in Table 1, the sample was predominantly female, White, and middle-aged. HD and HC participants did not differ significantly in terms of age, sex, or race/ethnicity. As expected, HD participants scored significantly higher than did HD participants on the SI-R and DASS scales. More than half of the HD participants had a comorbid depressive disorder.

3.2. Quality of life in hoarding disorder and healthy control participants

GLM of SF-36 scores for HD and HC participants yielded a significant main effect of group (F(1,76) = 67.58, p < 0.001, ηp² = 0.47), a significant main effect of SF-36 subscale (F(7,532) = 10.66, p < .001, ηp² = 0.12), and a significant group X subscale interaction (F(7,532) = 5.13, p < 0.001, ηp² = 0.06). Post hoc independent-samples t-tests (see Table 2, top) showed that the HD group scored significantly lower than did the HD group on all subscales, with effect sizes Cohen’s d in the large range (0.91–2.52). The largest effects were for emotional well-being and vitality; while the smallest (though still large) effects were for physical functioning and pain.
Pearson’s correlation coefficients between the SF-36 and DASS subscales were significant ($p < 0.05$, with $r$ values ranging from $-0.36$ to $-0.75$). When controlling for the DASS subscales, the GLM yielded a significant main effect of group ($F_{1,751} = 20.15$, $p < 0.001$, $\eta^2_g = 0.22$) and a significant main effect of SF-36 subscale ($F_{57,751} = 11.50$, $p < 0.001$, $\eta^2_g = 0.14$). The group X subscale interaction did not survive the Bonferroni correction ($F_{57,751} = 2.31$, $p = 0.025$, $\eta^2_g = 0.03$). Post hoc GLMs (see Table 2, bottom) showed that the HD group scored significantly lower than the HC group on emotional well-being, role limitations due to emotional problems, vitality, and general health, with effect sizes ($\eta^2_g$) ranging from 0.20 to 0.33.

### 3.3. Relationship between hoarding severity and quality of life

As shown in Table 3, in the entire sample (HD plus HC), for each of the SF-36 scales (physical functioning, social functioning, emotional well-being, role limitations due to physical health, role limitations due to emotional problems, vitality, pain, general health) depression, anxiety, and stress were significant predictors. Hoarding severity on the S-I-R improved the model significantly for social functioning, emotional well-being, role limitations due to physical health, role limitations due to emotional problems, vitality, and general health. In the HD sample, adding S-I-R to depression, anxiety, and stress improved the model significantly only for vitality (see Table 4).
impairments in physical functioning, role limitations due to physical health, and pain no longer differed between HD and HC participants when controlling for affective symptoms. This is noteworthy, because even though HD is associated with high rates of chronic medical illness (Tolin, Frost, Steketee, & Fitch, 2008), here the impairments in physical health-related QoL appear to be driven largely by affective factors. Other studies have demonstrated that affective symptoms (particularly depression) are associated with lower physical QoL ratings (Spitzer et al., 1995), beyond the effects of physical illness (Goldney, Phillips, Fisher, & Wilson, 2004). It will be important to clarify the unique contributions of hoarding and affective symptoms to physical functioning-related QoL in future studies. This will inform future treatment development and provide critical insight into the most relevant intervention targets in this population.

Independent of the HD diagnosis, the present results indicate that severity of hoarding symptoms predicts poorer QoL (beyond the effect of comorbid affective symptoms) in the domains of social functioning, emotional well-being, role limitations due to emotional problems, vitality, and general health. However, when the analysis was restricted to the HD sample, this was true only for vitality. Clinically, low energy is a common complaint among patients with HD, with 26% reporting significant fatigue using standardized tests (Nordsletten et al., 2013). The present results indicate that this low energy cannot be solely attributed to comorbid depressive symptoms. The lack of relationship of the other scales to HD severity, within the HD group, suggests that certain aspects of low QoL (i.e., social functioning, emotional well-being, role limitations due to emotional problems, and general health) are not necessarily linked to the severity of HD, but rather are impaired across the board in patients with at least moderate HD severity.

The major limitation of the present study is the absence of a clinical control group. Other psychiatric conditions, particularly depressive disorders, are associated with lower health-related QoL (Papakostas et al., 2004; Rapaport, Clary, Fayyad, & Endicott, 2005; Spitzer et al., 1995). Controlling for affective symptoms diminishes this concern to some extent, but additional research is recommended that compares QoL in HD patients to that of patients with other mental disorders, including those with OCD given mixed findings in this area (Albert et al., 2010; Fontenelle et al., 2010). Given that some HC vs. HD comparisons (e.g., physical functioning, pain) were no longer significant when controlling for affective symptoms, it appears that some domains of QoL may be better accounted for by general negative affect than hoarding symptoms per se. Indeed, SI-R scores generally did not predict QoL domains in the HD sample when controlling for DASS scores, suggesting that hoarding symptoms may not be relevant to certain health QoL domains beyond the contribution of overall negative affect. Another important limitation is that this was a sample of treatment-seeking HD patients, which may not represent the entire range of HD severity and cognitive deficits. Treatment-seeking patients may have greater insight into their current symptoms and overall level of impairment, which may have impacted their scores on self-report measures (including the SF-36). The QoL results thus may not generalize to non-treatment seeking HD samples. Furthermore, the study inclusion criteria (e.g., medication restrictions, at least moderate HD severity) may not be representative of all treatment-seeking HD patients. Finally, the sample was largely White and female, which likely does not reflect the HD population in the United States (Samuels et al., 2008).

HD is increasingly recognized as a severe psychiatric condition, distinct from OCD. It is associated with substantial psychiatric comorbidity (Frost et al., 2011), significant levels of functional impairment (Ong et al., 2015), high rates of work disability (Tolin et al., 2008), and high public health costs (Frost, Steketee, & Williams, 2000). The present study adds to this picture by demonstrating that HD is also associated with poor health-related QoL, beyond the effects of comorbid affective symptoms. Given findings that functional impairment can improve over the course of treatment for HD (Tolin, Frost, Steketee,

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### Table 4
Linear regression models predicting MOS short-form-36 (SF-36) scores from saving inventory-revised (SI-R) scores, controlling for depression, anxiety, and stress, which are common in patients with HD (Frost, Steketee, & Tolin, 2011). Specifically, self-reported impairments in physical functioning, role limitations due to physical health, and pain no longer differed between HD and HC participants when controlling for affective symptoms. This is noteworthy, because even though HD is associated with high rates of chronic medical illness (Tolin, Frost, Steketee, & Fitch, 2008), here the impairments in physical health-related QoL appear to be driven largely by affective factors. Other studies have demonstrated that affective symptoms (particularly depression) are associated with lower physical QoL ratings (Spitzer et al., 1995), beyond the effects of physical illness (Goldney, Phillips, Fisher, & Wilson, 2004). It will be important to clarify the unique contributions of hoarding and affective symptoms to physical functioning-related QoL in future studies. This will inform future treatment development and provide critical insight into the most relevant intervention targets in this population.

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& Muroff, 2015), it would be useful to determine whether health-related QoL improves following treatment as well.

Conflict of interest

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