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# Stigma and Shame as Barriers to Treatment for Obsessive-Compulsive and Related Disorders

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## Abstract

Limited research has examined barriers to treatment for obsessive-compulsive disorder (OCD), and no known studies have addressed barriers to treatment for trichotillomania (TTM) or skin picking disorder (SPD). Additionally, existing literature does not examine differences in barriers to treatment based on the content and severity of OCD obsessions. Previous literature has shown that shame and stigma may be an important reason for avoiding psychological treatment. This study examined the potential role of stigma and shame surrounding attitudes about treatment initiation for individuals with OCD, TTM, or SPD. Participants were recruited from study links posted on professional mental health websites. Included in the analyses were those who met diagnostic screening criteria for OCD, TTM, or SPD (n=587). Across disorders, the most frequently endorsed barrier was being "ashamed of my problems." Ethnic minorities endorsed more stigma/shame connected with family disapproval. Individuals with OCD were significantly more likely to report a fear of involuntary hospitalization. Content and severity of OCD obsessions impacted stigma/shame barriers, as those with high levels of unacceptable/taboo thoughts were at greater risk for experiencing stigma/shame. Implications of findings are discussed.

**Keywords:** Barriers to treatment; Obsessive-compulsive disorder; Trichotillomania; Skin picking disorder; Shame and stigma

## Introduction

Although effective treatments for obsessive-compulsive related disorders exist [1-3], nonetheless the average delay from onset of symptoms to initiating treatment is over ten years [4]. Additionally, obsessive-compulsive (OC) spectrum disorders without appropriate treatment tend to be chronic in nature [5,6]. Therefore, it is crucial that people with these spectrum disorders engage in the existing highly efficacious treatment approaches.

Limited research has examined barriers to treatment for obsessive-compulsive disorder (OCD). Extant research suggests financial factors, uncertainty regarding how to find the right treatment option, and belief that patients can overcome the symptoms without professional help are critical in preventing treatment engagement [7,8]. However, shame and stigma concerns are also highly prevalent. For example, 20.5% of those never treated from the National Anxiety Disorders Screening Day survey endorsed a fear of what others would think as a barrier to care [9]. Another study of treatment-seeking among those reporting having OCD in an Internet sample found that over half reported feeling ashamed of their problems [8], and similar concerns were reported by African Americans with an OCD diagnosis [10].

The existing literature, however, does not assess for differences in ability to obtain treatment based on the content and severity of obsessions. Williams, Mugno, Faber, and Franklin [11] noted that OCD is a phenomenologically heterogeneous disorder, and it is reasonable to infer that those with obsessions considered immoral in nature (e.g., sexual, violent, religious obsessions) may be particularly vulnerable to heightened levels of stigma and/or shame [7,12,13], which may pose an additional barrier to treatment. For example, people with obsessions about harming children may be reluctant to share these thoughts with professionals out of fear they would be considered deviant and subsequently shamed and ostracized. Therefore, it is plausible that the content of one's obsession may have a significant impact on whether or not treatment is sought and/or obtained.

Additionally, no current work has assessed factors associated with barriers to treatment for individuals with trichotillomania (TTM) or excoriation (skin-picking) disorder (SPD). However, people with trichotillomania may have obvious signs of the disorder in the form of bald patches, missing eyelashes, or missing eyebrows. People with skin picking may have red patches, scabs, and scars on the face, hands, or other places that are not easy to conceal. Friends and family members may have ridiculed sufferers for their inability to stop the behavior and the subsequent visible results. Research has found individuals suffering from trichotillomania and skin-picking disorder experience elevated levels of shame [13], but how the shame impacts their decision to seek treatment remains unclear.

Because of the notable gap in the literature, new research is needed to develop a more comprehensive understanding of barriers to treatment. Such information can potentially be utilized to shape targeted interventions, thereby decreasing the impact of the disorder and improving rates of treatment initiation. The aim of the current investigation is to obtain a better understanding of the barriers to treatment for OCD, trichotillomania and skin-picking disorder. Based on previous findings among those with OCD, we hypothesized that shame, stigma and doubt about the efficacy of treatment will be more highly endorsed than logistical and financial factors for all three OC spectrum disorders under investigation. Additionally, we predicted that for OCD, the content of the obsession would affect the outcome;

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specifically participants who endorse higher levels of sexual, violent, or religious obsessions (unacceptable/taboo thoughts) would experience more stigma and shame-related barriers to treatment than participants with other types of obsessions.

## Methods

### Participants

The study was approved by the University of Houston – Clear Lake Institutional Review Board. Participants were recruited via study links posted on the following online professional websites: Houston OCD Program, International Obsessive Compulsive Disorder Foundation, Peace of Mind Foundation, and the Trichotillomania Learning Center. In total, 3,109 individuals provided online consent and initiated the survey. Of the total sample, 587 participants screened positive for OCD, trichotillomania, or skin-picking disorder and completed the survey. The data from the individuals who screened positively (n=587) are used for the study analyses.

The majority of the sample (75.6%) was female and the mean age was 30.2 (SD=10.7) years. Most participants identified as non-Hispanic White/European American (82.5%). Approximately half the sample (55.2%) was either married or in a relationship. Of the 587 participants, 45.4% had trichotillomania, 27.8% had OCD, and 26.7 % had skin-picking disorder (Table 1).

### Procedures

Data collection occurred from January 2013 through February 2014. Participants who visited the aforementioned professional websites during this time period and clicked on the web link proceeded to the survey website voluntarily. After providing informed consent participants completed questionnaires that obtained information relating to basic demographic information, diagnoses, severity of symptoms, and barriers to treatment. Data-checking measures were implemented to assess for data validity (e.g., to ensure that participants did not select the same response for all questions or that the time spent on the survey was not unreasonably brief).

| Characteristic | Trichotillomania | OCD | Skin picking disorder |
|---|---|---|---|
| | (*N*=268) | (*N*=164) | (*N*=155) |
| Age [Mean(S.D.)] | 29.7 (9.9) | 28.4 (10.2) | 33.1 (12.0) |
| Gender (%) | | | |
| Female | 88.1 | 49.4 | 81.9 |
| Race/Ethnicity (%) | | | |
| non-Hispanic White/ European American | 81.7 | 76.8 | 89.7 |
| Asian/East Indian American | 3.7 | 7.9 | 2.6 |
| Hispanic American | 3.0 | 6.1 | 1.3 |
| Black/African American | 2.2 | 1.8 | 1.3 |
| Other | 9.5 | 6.6 | 5.2 |
| Relationship status (%)[a] | | | |
| Married/Relationship | 62.3 | 50.0 | 64.5 |
| Single | 39.9 | 47.5 | 32.2 |
| Divorced | 4.5 | 6.1 | 6.5 |
| Symptom severity | 16.6 (6.0)[b] | 60.0 (20.4)[c] | 10.1 (4.8)[d] |

**Note:** [a]denotes more than one answer was permitted
[b]assessed by the massachusetts general hospital hairpulling scale
[c]assessed by the dimensional obsessive compulsive scale
[d]assessed by the skin picking scale

**Table 1:** Description of total sample.

### Measures

Diagnostic screening measures, wetterneck-hart OCD screener: A 4-item screening instrument used to assess for the presence of obsessive-compulsive disorder [1,14].

Trichotillomania checklist: A 9-item screening measure modeled after diagnostic criteria that assesses for the presence of hair pulling (previously used [15]).

Skin picking checklist: A 9-item screening tool modeled after diagnostic criteria that assesses for the presence of skin picking behaviors.

Dimensional obsessive compulsive scale: The DOCS is a 35-item measure that assesses an individual's level of distress associated with symptoms focused on contamination, harm, unacceptable thoughts, and/or symmetry. To better capture the breadth of symptoms within the unacceptable thoughts category, an expanded version of the measure was used that exploded this category into three additional scales for sexual thoughts [16,17], violent thoughts, and scrupulous/religious concerns. Cronbach's alphas for the 5 religious, 5 sexual, and 5 violent items were 0.96, 0.96, and 0.95, respectively.

Massachusetts general hospital hairpulling scale (MGH; Keuthen et al.): The MGH is a 7-item assessment instrument that measures the severity of hair-pulling based on urge to pull, actual pulling, perceived control and the distress associated with pulling.

Skin picking scale (SPS; Keuthen et al.): The SPS is a 6-item measure that assesses the severity of skin picking and distinguishes self-injurious and non-self-injurious skin pickers.

Barriers to treatment questionnaire (BTQ): The BTQ is a 17-item questionnaire that assesses barriers to treatment seeking behaviors such as 1) logistical and financial factors, 2) shame and stigma concerns, and 3) treatment perception factors [8].

## Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used for all analyses. Analyses were two tailed and statistical significance was determined by $\alpha$=0.05. The a priori analysis consisted of a one-way ANOVA and was conducted to assess for significant differences in the barriers to treatment items across diagnoses. Additional analyses were conducted to assess if the content of OCD obsessions affected the endorsement of barriers to treatment. Due to participants' high level of comorbidity amongst OCD obsessional types, post hoc analyses were conducted to assess for significant differences in barriers to treatment across the different types of obsessions the severity of the symptoms was factored into the analyses. The symptom severity scores from each obsession dimension were split into high versus low severity with the upper quartile of scores coded as high severity and the lower quartile scores coded as low severity. Pearson Chi-Square analyses were conducted to assess for significant differences in barriers to treatment for each OCD dimension dependent on the severity of symptomatology. Post hoc analyses were also conducted to assess for differences in barriers to treatment depending on race and ethnicity.

## Results

### A Priori analyses

Barriers to treatment: Across the OC spectrum disorders: Of the 17 items from the BTQ, six-items were reported as a barrier to treatment by the majority (i.e., over 50%) of participants, across all three diagnoses.

Half of these barriers were related to stigma/shame concerns (i.e., "ashamed of my problems"; "ashamed of needing help"; "worried what others may think of me if they knew I was in treatment"). Additionally, logistical (i.e., "unsure who to see/where to go"), financial (i.e., "worried about the cost") and personal (i.e., "wanted to handle it on my own") factors were also endorsed by over half of all participants (Table 2).

While the majority (82.4%) of items were endorsed by at least one-quarter of the overall sample, significant differences between diagnostic conditions was found on three items. Participants were significantly more likely to endorse "scared of being put in a hospital against my will," depending on their diagnosis [$F(2,584)=10.91$, $p<0.001$]; more specifically, participants with OCD were approximately twice as likely to select the item as a treatment barrier compared to those who screened positive for TTM or SPD, respectively (39.0% vs. 20.1%; 21.3%). Additionally, a significant difference between conditions was found for the question "I could not get an appointment" [$F(2, 584)=8.43$, $p<0.001$], with individuals with OCD being at least twice as likely to report not being able to get an appointment compared to those with trichotillomania or skin-picking disorder (16.5% vs. 6.3% and 5.2%, respectively). Lastly, a significant difference between participants with OCD versus SPD was found for the item "I thought it would be too inconvenient or take too much time" [$F(2, 584)=3.68$, $p<0.05$]. Participants with SPD were approximately 1.5 times more likely to endorse the item compared to those with OCD.

| Characteristic | Percentages (%) | | | |
|---|---|---|---|---|
| | Trichotillomania | OCD | Skin-picking disorder | Total Sample |
| | (*n*=268) | (*n*=164) | (*n*=155) | (*N*=587) |
| **Stigma/Shame Factors** | | | | |
| Ashamed of my problems | 72.0 | 75.0 | 74.8 | 73.6 |
| Ashamed of needing help | 60.8 | 65.2 | 70.3 | 64.6 |
| **Worried what others' may think of me** | | | | |
| if they knew I was in treatment | 58.2 | 65.9 | 56.8 | 60.0 |
| Uncomfortable speaking with a health professional | 38.1 | 48.2 | 44.5 | 42.6 |
| Fear of being criticized by family | 32.5 | 40.2 | 32.3 | 34.6 |
| Scared of being put in a hospital against my will | 20.1^ | 39.0*^ | 21.3* | 25.7 |
| **Perception/Satisfaction Factors** | | | | |
| Wanted to handle it on my own | 70.5 | 73.8 | 71.6 | 71.7 |
| Did not think treatment would work | 50.7 | 44.5 | 45.2 | 47.5 |
| Received prior treatment that didn't work | 40.7 | 29.9 | 26.5 | 33.9 |
| Unsatisfied with services that were available | 24.6 | 22.0 | 24.5 | 23.9 |
| Unable to choose the provider I wanted to see | 14.9 | 18.9 | 19.4 | 17.2 |
| **Logistical Factors** | | | | |
| Unsure who to see/where to go | 70.1 | 66.5 | 74.8 | 70.4 |
| Too inconvenient/take too much time | 42.9 | 36.0* | 51.0* | 43.1 |
| Transportation or scheduling issues | 28.0 | 25.6 | 21.9 | 25.7 |
| Could not get an appointment | 6.3^ | 16.5*^ | 5.2* | 8.9 |
| **Financial Factors** | | | | |
| Worried about the cost | 59.7 | 53.7 | 54.2 | 56.6 |
| Health insurance would not cover treatment | 41.8 | 39.0 | 38.1 | 40.0 |

**Notes:** *denotes a significant difference between the OCD and skin-picking groups
^denotes a significant difference between the OCD and trichotillomania groups

**Table 2:** Barriers to treatment breakdown.

## Post hoc analysis

Barriers to treatment: Across race and ethnicity: To examine differences based on race and ethnicity, participants were divided into two groups, non-Hispanic White (n= 484) compared to all others (n=103). Minorities were placed in a single group because there were not enough to examine differences separately. Combining all conditions, significant differences were found for the following barriers to treatment: "afraid of being criticized by my family if I sought help" (32.0% vs. 46.6%, p=0.005), "troubles with transportation or scheduling," (23.8% vs. 53.7%, p=0.018), and "could not choose the provider I wanted" (15.7% vs. 32.1%, p=0.036).

Barriers to treatment: OCD content and severity: Significant differences were found between some of the stigma/shame treatment barriers for participants who had high versus low severity of "unacceptable thoughts" obsessions (e.g., violent, sexual, or religious obsessions). No significant differences between OCD content and severity was found for individuals with contamination or symmetry obsessions. Participants with high severity of violent or sexual obsessions were significantly more likely to report fears about being hospitalized against their will compared to participants with low severity of those types of obsessions [Wald chi-square (1)=7.398; p=0.007; Wald chi-square (1)=6.727; p=0.009]. No significant difference between symptom severity and obsessional content was found for the other symptom dimensions for the fear of hospitalization barrier to treatment item. However, participants with high severity of religious obsession were significantly more likely to report concern of being criticized by family than participants with low severity of religious obsessions [Wald chi-square (1)=6.499; p=0.011, respectively] or those with any of the other obsession dimensions. Table 3 describes a complete depiction of the stigma/shame items and treatment barriers that were associated with the content and severity of OCD, only items with significant findings are shown.

## Discussion

Across disorders, the most frequently endorsed barrier was being "ashamed of my problems," followed closely by "wanting to handle it on my own," and not knowing "where to go for help." These concerns are consistent with previous studies of OCD [2,8] however, the current study found a higher degree of shame/stigma related concerns than previous studies. For example "felt ashamed of my problems" was endorsed by three-quarters of those with OCD in the current study compared to just over half of the Internet sample in Marques et al. (75.0% vs. 53.2%). This discrepancy may be due to differences in the symptom dimensions endorsed by both study samples. The type of participants' obsessions was not included in the Marques et al. sample; our sample, however, did have a heightened amount of participants with elevations in the unacceptable thoughts dimension. If the Marques sample had fewer participants with unacceptable thoughts then it is possible that the lower levels of stigma/shame barriers to treatment may be related to differences in the percentage of the participants suffering from unacceptable thoughts.

When examining ethnic and racial differences in barriers to

| Characteristic | Endorsed response (%) | | Chi-square | P-value |
|---|---|---|---|---|
| | Low severity | | | |
| Scared of being put in a hospital against my will | | | | |
| Sexual obsessions | 17.2 | 48.5 | 6.727 | .009 |
| Violent obsessions | 25.5 | 52.4 | 7.398 | .007 |
| Unacceptable thoughts obsessions | 25.0 | 50.0 | 4.912 | .027 |
| **Ashamed of my problems** | | | | |
| Sexual obsessions | 58.6 | | 5.335 | .021 |
| Scrupulous obsessions | 62.7 | | 8.093 | .004 |
| Unacceptable thoughts obsessions | 55.6 | | 5.845 | .016 |
| **Did not think treatment would work** | | | | |
| Sexual obsessions | 20.7 | | 11.581 | .001 |
| Unacceptable thoughts obsessions | 30.6 | | 9.187 | .002 |
| Ashamed of needing help | | | | |
| Scrupulous obsessions | 54.2 | 76.6 | 5.687 | .017 |
| **Worried what others' may think of me if they knew I was in treatment** | | | | |
| Violent obsessions | 56.4 | 76.2 | 4.112 | .043 |
| Scrupulous obsessions | 55.9 | 83.0 | 8.783 | .003 |
| **Uncomfortable speaking with a health professional** | | | | |
| Violent obsessions | 30.9 | 64.3 | 10.704 | .001 |
| Unacceptable thoughts obsessions | 27.8 | 50.0 | 3.831 | .050 |
| Fear of being criticized by family | | | | |
| Scrupulous obsessions | 28.8 | 53.2 | 6.499 | .011 |
| Wanted to handle it on my own | | | | |
| Scrupulous obsessions | 64.4 | 83.0 | 4.540 | .033 |

**Table 3:** Content of obsession, severity of OCD and significant stigma/shame & perception/satisfaction barriers to treatment.

treatment overall, a few unique concerns emerged for ethnic minorities, most notably stigma and shame connected to family disapproval. Minorities tend to underutilize mental health treatment for OCD, due in part to negative perceptions about Western mental health care, and they also tend to have closer relationships with family members [16]. Thus stigmatizing reactions from family may be more distressing to minorities as compared to their non-Hispanic White counterparts. Many ethnic groups do not tolerate members obtaining help outside of their families and close-knit communities, which is consistent with reports of greater difficulty in finding an acceptable mental health provider. In fact, families may be more willing to tolerate OC symptoms than the afflicted individual obtaining formal mental health services.

On the whole, individuals with OCD, trichotillomania, and skin-picking disorder experienced similar barriers to treatment at similar rates. However, a few key distinctions between groups emerged. Individuals with OCD were approximately twice as likely to report a fear of being involuntarily hospitalized. While the reasons behind the fears were not assessed, it is possible that the increased endorsement of this item among individuals with OCD relates to the fact that the content of OCD can manifest in socially and morally reprehensible ways. Further support for this hypothesis was found by the result that individuals with high severity of violent or sexual obsessions were significantly more likely to report a fear of involuntarily hospitalization compared to those with other types of obsessions. It is logical that individuals who suffer from intrusive thoughts of harming other people and/or obsessions related to pedophilia, rape, or other repugnant sexual acts may not be aware that these fears are common manifestations of OCD. Even if they do believe they have OCD, such individuals may be concerned about misdiagnosis [18] and subsequent involuntary hospitalization. Additionally, it was found that participants with a higher severity of unacceptable thoughts (violent, sexual or religious obsessions) were more likely to endorse stigma/shame or concerns about treatment as barriers compared to those with obsessions related to contamination or symmetry. While differences were found between the type of unacceptable thought and specific barriers to treatment, individuals with violent, sexual or religious obsessions appear to be a particularly vulnerable group that is more susceptible to stigma and shame surrounding treatment. Thus, addressing issues of stigma and shame in patients initially presenting for treatment of OC related disorders may be critical, particularly for those with unacceptable/taboo thoughts. Specific targeted shame-reducing strategies may be an important therapeutic intervention to facilitate treatment in such individuals.

Those with OCD were at least twice as likely to report being unable to get an appointment compared to those with TTM or SPD. Finding effective treatment for OCD and related conditions can be difficult. Taylor et al. [19] note that many individuals do not have access to cognitive-behavioral therapy for OCD because of a lack of therapists who use empirically-supported treatments, particularly in rural areas. Nakagawa et al. [20] notes that most clinicians do not receive training in empirically-supported treatments in general [21], resulting in a lack of behavioral therapists who can effectively treat OCD, particularly for individuals without overt rituals or the more easily recognized symptoms [22]. As a result, many have difficulty locating qualified providers in their communities.

However, it was not assessed whether participants previously tried to obtain an appointment. Therefore, it cannot be determined whether individuals with OCD have more difficulty getting an appointment compared to those with TTM or SPD or whether individuals with trichotillomania or skin-picking disorder did not report difficulty getting an appointment because they have not previously sought treatment. Preliminary evidence was found for the latter, since individuals with skin-picking disorder were significantly more likely to think treatment would be too inconvenient/take too much time compared to those with OCD. Furthermore, a similar trend was found for participants with trichotillomania believing treatment would be too inconvenient compared to those with OCD.

## Limitations

As previously mentioned, treatment history was not obtained. Therefore, it is unclear how many participants are currently or have ever been in treatment, and how this experience may have impacted responses. It is unknown if the barriers to treatment endorsed by each participant permanently or temporarily impeded treatment initiation or had any effect on engagement in treatment. In fact, it could be that greater distress surrounding unacceptable/taboo thoughts results in earlier treatment-seeking [4]. Additionally, the study sample was comprised of individuals who visited the specific websites that displayed the study link; therefore, the study sample may not be representative of the treatment-seeking population or the afflicted population at large, and thus caution must be taken when considering these findings.

## Future Directions

Since approximately half of participants from each of the three mental health conditions reported the belief that treatment would not work, one important avenue for further research should be to assess the efficacy of a psycho-educational-based intervention targeted to increase awareness regarding first-line treatment approaches, and their strong efficacy. Previous

research has shown that beliefs surrounding the cause of OCD can heavily influence perceptions about the proper avenues for treatment, so accurate information about the cause of these disorders should be a component of any educational intervention [23].

Future work should ask individuals to not only select which treatment barriers impede them from seeking help but to also rank the strength of each factor. For example, while someone may select both being concerned about the cost and feeling ashamed of their problems, it is possible that the cost-related concern is of minimal impact whereas the driving force delaying treatment may be primarily related to shame or vice versa. The present study could not make such a determination.

A study of demographic factors related to obtaining treatment is also an important area in need of further study. This investigation did not include enough ethnic/racial minorities to examine differences in barriers to treatment by specific ethnic/racial group, yet previous work has shown that concerns about discrimination may be a deterrent to help-seeking for OCD [2]. As prior studies have implicated cost of treatment as a major barrier, the role of SES and insurance coverage are also important factors that require additional exploration. A more comprehensive understanding of treatment barriers and how they affect various sub-populations among those afflicted will provide important clinical and public health related information.

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