



## Clinical features of olfactory reference syndrome: An internet-based study



Jennifer L. Greenberg<sup>a,b,c,\*</sup>, Ashley M. Shaw<sup>a,b,c,d</sup>, Lillian Reuman<sup>a,b,c,e</sup>,  
Rachel Schwartz<sup>a,b,c,f</sup>, Sabine Wilhelm<sup>a</sup>

<sup>a</sup> Massachusetts General Hospital, Simches Research Building, 185 Cambridge Street, Suite 2200, Boston, MA 02114, United States

<sup>b</sup> Harvard Medical School, Simches Research Building, 185 Cambridge Street, Suite 2200, Boston, MA 02114, United States

<sup>c</sup> Department of Psychiatry, Simches Research Building, 185 Cambridge Street, Suite 2200, Boston, MA 02114, United States

<sup>d</sup> Department of Psychology, University of Miami, United States

<sup>e</sup> Department of Psychology, University of North Carolina, Chapel Hill, United States

<sup>f</sup> Department of Psychology, University of Pennsylvania, United States

### ARTICLE INFO

#### Article history:

Received 5 June 2015

Received in revised form 3 November 2015

Accepted 4 November 2015

#### Keywords:

Jikoshu-kyofu

Malodour

Obsessive-compulsive spectrum disorders

Olfactory reference syndrome

Taijin kyofusho

Somatiform disorders

### ABSTRACT

**Objective:** Preoccupation with perceived bodily odor has been described in neuropsychiatric disorders for more than a century; however, empirical research on olfactory reference syndrome (ORS) is scarce. This study investigated the phenomenology of ORS in a broadly ascertained, diverse sample.

**Method:** Data were obtained from 253 subjects in an internet-based survey that operated from January – March 2010. Measures included the Yale-Brown Obsessive Compulsive Scale Modified for ORS (ORS-YBOCS), Work and Social Adjustment Scale (WSAS), Depression Anxiety Stress Scales (DASS), and symptom specific questionnaires developed for this study.

**Results:** Individuals reported, on average, moderately severe ORS symptoms. The average age of onset of ORS symptoms was 21.1 years, with 54% reporting a chronic, unremitting course. Individuals endorsed a lifetime average of two malodorous preoccupations, most commonly stool, garbage, and ammonia. Odors were most often reported to emanate from the armpits, feet, and breasts. Nearly all participants engaged in time-consuming rituals to try to hide or fix their perceived malodor (e.g., checking and camouflaging). Eighteen percent reported poor or delusional insight and 64.0% reported ideas or delusions of reference. More severe ORS symptoms were moderately associated with female gender, poorer insight, and higher levels of impairment (in work, social leisure, ability to maintain close relationships, and consecutive days housebound).

**Conclusion:** This is the largest study on ORS to date. Results underscore the clinical significance and psychosocial impact of this understudied disorder, and highlight the need for subsequent research to examine clinical features and inform treatment.

© 2015 Elsevier Inc. All rights reserved.

### 1. Introduction

Persistent preoccupation with body odor has been described in various neuropsychiatric and psychological disorders since 1891 [1]. Olfactory concerns are a prominent feature in various conditions cross-culturally (e.g., *Taijin kyofusho* in Japan and Korea) and across diagnoses (e.g., olfactory hallucinations in schizophrenia, major depression, and eating disorders) [2]. Olfactory reference syndrome (ORS), a severe and impairing psychiatric condition characterized by a preoccupation that one emits a foul or offensive odor, was first introduced by Pryse-Phillips [3] in a detailed description of 36 cases of individuals

with olfactory symptoms. The clinical features and associated symptoms of individuals with perceived body odor have subsequently been noted in various case reports and series [3–12]. In case reports, individuals with ORS have been shown to engage in time-consuming rituals aimed at masking or fixing the odor [4,9,12,13], avoid social situations [11], experience impaired work functioning [4], exhibit significant distress [5], report suicidal ideation and past suicide attempts [3,12,14,15], and sometimes become housebound [4]. Despite the marked severity and impairment associated with ORS, empirical research on ORS is extremely limited.

ORS was first categorized as an atypical somatoform disorder in the DSM-III [16] and later as an example of delusional disorder of somatic type in DSM-IV-TR [17]. However, its categorization has been controversial [4,15]. Recent research findings challenged the appropriateness of categorizing ORS as a delusional disorder since the core belief is not always held with delusional conviction [12]. Moreover, the clinical

\* Corresponding author.

E-mail addresses: [jlgreenberg@mg.harvard.edu](mailto:jlgreenberg@mg.harvard.edu) (J.L. Greenberg),  
[a.shaw6@umiami.edu](mailto:a.shaw6@umiami.edu) (A.M. Shaw), [reuman@unc.edu](mailto:reuman@unc.edu) (L. Reuman),  
[raschw@mail.med.upenn.edu](mailto:raschw@mail.med.upenn.edu) (R. Schwartz), [swilhelm@mg.harvard.edu](mailto:swilhelm@mg.harvard.edu) (S. Wilhelm).

presentation of ORS (i.e., obsessions about personal odor and compulsive odor-related behaviors) and its preferential response to selective serotonin reuptake inhibitors (SRIs) overlap significantly with obsessive-compulsive spectrum disorders and suggest a more accurate classification as part of the obsessive-compulsive and related disorders [5]. Indeed, the DSM-5 Anxiety, Obsessive-Compulsive Spectrum, Posttraumatic, and Dissociative Disorders Workgroup highlighted the importance of studying ORS and suggested adding ORS to the Appendix of Criteria Sets Provided for Further Study [18]. Olfactory reference syndrome currently appears in DSM 5 under “Other Specified Obsessive Compulsive Disorders” as *Jikoshu-kyofu*, a variant of *taijin kyofusho* characterized by fear of having an offensive body odor [19].

In order to better understand the classification and treatment of ORS, it is critical to first investigate its clinical and epidemiological features. Thus far, research on ORS has been limited to case reports, case series, and theoretical papers. Samples have included individuals receiving treatment in specialty OCD treatment clinics [5,12] and inpatient samples [3], which may not accurately reflect the prevalence and features of ORS in the general population. Little is known about the features of ORS in a widely ascertained community sample.

The current study expands on previous findings by investigating the clinical features of ORS in a diverse, community sample. We used internet sampling procedures in order to ascertain a broad sample of individuals with self-reported ORS and to increase the generalizability of the results. Since patients with ORS often feel ashamed and embarrassed about their concerns [3], we hoped that the anonymity of the project would allow individuals who may otherwise be too ashamed to discuss their concerns or seek mental health treatment to participate. Although internet sampling procedures are not without limitations, several studies have demonstrated that data gathered via the Internet may be as reliable as data collected with paper and pencil measures [20–22].

Understanding the clinical features of ORS and putative overlap with other disorders (e.g., obsessive-compulsive disorder [OCD] and body dysmorphic disorder [BDD]) will help inform diagnostic classification and treatment. This study is the first systematic examination of the clinical features of ORS in the general population. The primary purpose of this study was to enhance our understanding of the diagnosis and treatment of individuals suffering from ORS. Since ORS is often undiagnosed or misdiagnosed in clinical settings, gathering information on the clinical presentation of ORS will aid clinicians in diagnosing future patients.

## 2. Methods

### 2.1. Participants

The Institutional Review Board at the Massachusetts General Hospital approved all recruitment and study procedures. Participants were recruited online (e.g., advertisements on internet search engines and support group forums), through letters to local clinicians, and flyers posted in the community. Recruitment materials provided a link to the survey, which operated from January 2010 – March 2010. Participants were included if they were 18 years or older, proficient in English, and had self-reported ORS (as indicated by a response of yes to the following two questions: 1) “Are you very worried about how you smell? 2) Do you spend a lot of time thinking about your body odor concerns and wish you could think about them less?”; and a score of >20 on the Yale Brown Obsessive-Compulsive Scale Modified for ORS [ORS-YBOCS; description below]). Exclusion criteria included existence of a known medical condition that could potentially account for malodor (e.g., trimethylaminuria [TMAU], irritable bowel syndrome, gastroesophageal reflux disease, and plantar hyperhidrosis). Of the 509 responses received, 176 were ineligible for the following reasons: ORS-YBOCS total score < 20 ( $n = 89$ ), did not complete all questions to determine ORS diagnosis ( $n = 50$ ), known/diagnosed medical condition that could account for malodor ( $n = 25$ ), and 12 participants were under age 18. These inclusion/exclusion criteria were informed by comparable studies in other

disorders considered be related to OCD such as BDD [23] and BDD by proxy [24]. Surveys containing invalid data ( $n = 80$ ; e.g., duplicate surveys containing identical information on all items) were excluded from analyses. Thus, the final sample included 253 subjects.

### 2.2. Procedure

All measures were completed through an anonymous online survey supported by SurveyMonkey (<http://www.surveymonkey.com>). Upon entering the survey, participants were directed to an informed consent page. Informed consent was obtained after the nature of the procedures had been fully explained. The survey took approximately 45 min to complete. For their participation, individuals received a \$10 gift certificate. To prevent duplicate responses, only one survey could be submitted per unique IP address.

### 2.3. Measures

The Yale-Brown Obsessive Compulsive Scale Modified for ORS (ORS-YBOCS) is a 12-item self-administered scale that rates the severity of ORS symptoms over the past week. It was used to determine eligibility and severity of ORS symptoms. The ORS-YBOCS was modified with permission from the BDD-YBOCS [25] and from the self-report Y-BOCS [26,27]. Each item is scored along a Likert scale ranging from 0 (*least extreme*) to 4 (*most extreme*), with higher total scores indicating more severe ORS symptoms (range 0–48). A score of  $\geq 20$  on the ORS-YBOCS was used to determine eligibility and was selected based on the scale threshold of the BDD-YBOCS that corresponds to a diagnosis of BDD [score of 20; 28]. Question 11 of the ORS-YBOCS (“Do you think your body odor is reasonable or rational?”) was used to measure level of insight, with a score of 0 indicating good insight (“I think that my body odor concerns and behaviors are unreasonable or excessive”) and a score of 4 indicating poor insight (“I am sure my body odor concerns or behaviors are reasonable, no matter what anyone says”). To our knowledge, no measures to assess ORS existed at the time of the study. Thus, we developed questions to assess: (1) factors influencing ORS onset and maintenance; (2) odors of concern; (3) body parts of concern; and (4) ORS-related thoughts, behaviors, and feelings. Questions contained a combination of forced-choice (e.g., Has anyone ever told you that your preoccupation with body odor is excessive?) and open-ended (e.g., Please describe your specific concern for each odor checked) items. The Work and Social Adjustment Scale [WSAS; 29] is a 5-item self-report measure that was used to assess impaired functioning. Each item corresponds to a discrete domain of functioning (e.g., work, social, leisure) and is scored from 0 (*not at all impaired*) to 8 (*very severely impaired*), with higher scores suggesting greater impairment. The WSAS demonstrates good internal consistency (0.70–0.94) and test-retest reliability ( $r = 0.73$ ). The Depression Anxiety Stress Scales [DASS; 30] is a 21 item self-report measure that was used to assess symptoms of depression, anxiety, and stress. Each item is scored from 0 (*did not apply to me at all over the last week*) to 3 (*applied to me most of the time over the past week*), with higher scores suggestive of more severe pathology. Excellent psychometric properties have been found [31,32].

### 2.2. Statistical analysis

Study analyses addressed demographics, phenomenology (e.g., body odors of concern), associated features (e.g., insight, avoidance, impairment), and course of illness. Data are reported for the final sample of subjects who by self-report met the aforementioned study criteria ( $n = 253$ ). Means and standard deviations were calculated. A missing ORS-YBOCS total score was imputed if one question (< 10%) was unanswered, by assigning the missing item the overall mean score [33]. The ORS-YBOCS, WSAS, and DASS were log/square root transformed to achieve normality. Pearson correlations were used to examine the relationships between variables of interest. Independent t-tests were used to examine mean

Download English Version:

<https://daneshyari.com/en/article/949169>

Download Persian Version:

<https://daneshyari.com/article/949169>

[Daneshyari.com](https://daneshyari.com)