



# Prevalence of olfactory reference disorder according to the ICD-11 in a German university student sample

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Accepted: 14 November 2023 / Published online: 1 December 2023  
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## Abstract

Olfactory reference disorder (ORD) is included as a new diagnosis in the 11th revision of the International Classification of Diseases (ICD-11). Its core symptom is persistent preoccupation with the belief that one is emitting a foul or offensive body odor or breath that is usually not perceptible to others. However, there is a lack of knowledge about the prevalence of ORD. In particular, the prevalence of the disorder has not yet been investigated using the ICD-11 diagnostic features. Therefore, this study aimed to assess the point prevalence of ORD according to the ICD-11. A total of 275 German students at university or college, aged 18–53 years, participated in an anonymous internet-based survey assessing ICD-11 essential features for ORD. The prevalence of ORD was 5.5%. Participants who met the self-rated features for ORD reported suicidal thoughts significantly more frequent than participants who did not meet the features for ORD. More than half of the participants with probable ORD reported ideas of reference and at least a strong conviction of their beliefs, suggesting poor insight. In the total sample, single symptoms of ORD were frequent. Persistent preoccupation with the belief of malodor was the most common single symptom. Distress and impairment linked to ORD symptoms were frequent. Our results suggest that ORD may be relatively common in university students and highlight the importance of future studies investigating the epidemiology of ORD as well as its suitable treatment.

**Keywords** Olfactory reference disorder · ICD-11 · Prevalence · Suicidal thoughts · University students

## Introduction

Olfactory reference disorder (ORD) is included as a new diagnosis in the category of obsessive–compulsive and related disorders in the 11th revision of the International Classification of Diseases (ICD-11) (World Health Organization [WHO], 2019). Its core symptom is a persistent preoccupation with the belief that one is emitting a foul or

offensive body odor or breath that is usually not perceptible to others (WHO, 2019). According to the ICD-11, essential (required) features in the Clinical Descriptions and Diagnostic Requirements (CDDR) involve excessive self-consciousness about the perceived odor, time-consuming repetitive behaviors (e.g., checking for body odor or odor source, excessive washing behavior), excessive camouflaging (e.g., by using perfume or deodorant), or reassurance seeking as well as the avoidance of (social) situations that increase distress (e.g., being close to another person) (WHO, 2019). In addition to these general diagnostic requirements, the ICD-11 also allows for the differentiation into three different specifiers of ORD. A distinction is made between the classification “with fair to good insight,” “with poor to absent insight” and an unspecified residual category (WHO, 2019). Symptomatology is accompanied with significant distress or severe psychosocial impairment; school or occupational losses, impairment of interpersonal relations and intimate relationships up to social isolation are common consequences (Feusner et al., 2010; Greenberg et al., 2016; Pryse-Phillips, 1971). In addition, several studies report high

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rates of suicidal ideation and attempted suicide in individuals with ORD, further underlining the suffering associated with the disorder (Phillips & Menard, 2011; Prazeres et al., 2010; Pryse-Phillips, 1971). In the patient sample described by Prazeres et al. (2010), 64.3% of their 14 ORD patients reported lifetime suicidal ideation and 21.4% past suicidal behavior. Pryse-Phillips (1971) found that 43% of his 36 ORD patients had suicidal ideas or exhibited suicidal behavior. In another patient sample, Phillips and Menard (2011) found that 68.4% of their 20 patients diagnosed with ORD reported lifetime suicidal ideation, while 1.6% had made suicide attempts.

Indeed, cases of preoccupation with the persuasion that one is emitting a foul body odor have been reported across cultures for over a century (Feusner et al., 2010). ORD has been previously described in the literature under different terms and categorization (Feusner et al., 2010; Greenberg et al., 2016). As such, ORD is also known as “*Jikoshu-kyofu*,” which is listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) under the section “Other Specified Obsessive Compulsive and Related Disorders.” Therein, “*Jikoshu-kyofu*” is defined as the fear of having an offensive body odor; this is a variant form of the culturally bound syndrome “*taijin kyofusho*” - a disorder of interpersonal fear implemented in a Japanese diagnostic system. The syndrome includes symptoms of social phobia, body dysmorphic disorder and delusional disorder (American Psychiatric Association, 2013), however, in the DSM-5, no clear diagnostic criteria have been defined.

Nonetheless, particularly in the Western world, ORD is largely unknown in clinical practice and is markedly understudied in scientific research worldwide. Specifically, the literature on ORD is comprised mainly of reports providing anecdotal vignettes or case descriptions, while there is also very limited reliable information about its epidemiology. There is a lack of basic knowledge about the disorder, including its prevalence which is currently unclear. To the best of our knowledge, only four studies have estimated the prevalence of ORD (Kasahara & Kenji, 1971; Schmidt et al., 2017; Zhou et al., 2018). These studies indicate that ORD might be comparatively common, however, due to a lack of standardized diagnostic criteria, the ORD diagnoses were assessed with different criteria. In addition, there is still no validated measuring instrument for assessing the disorder. In a survey among Japanese university students, Kasahara and Kenji (1971) found that 2.1% of their participants had been concerned with emitting a strange body odor during the past year. Zhou et al. (2018) assessed the prevalence of ORD by means of the self-administered Yale Brown Obsessive-Compulsive Scale Modified for ORD (ORS [Olfactory Reference Syndrome]-YBOCS; description below) in a Chinese university student sample and found an ORD prevalence rate of 2.4%. The ORS-Y-BOCS contains

twelve items that capture the severity of ORD symptoms over the past week. Items assess preoccupation with body odor (time occupied, interference with functioning due to the preoccupation, resulting distress, resistance, control), repetitive behaviors done in response to the preoccupation with body odor (time spent, interference with functioning, distress if the behaviors are prevented, resistance, control), insight regarding the perceived body odor, and avoidance of activities because of the perceived odor. Items are rated from 0 (no symptoms) to 4 (extremely severe symptoms). The ORS-YBOCS is a modified version of the BDD-YBOCS (Phillips et al., 1997). Zhou et al. (2018) used a total score of  $\geq 20$  on the ORS-YBOCS to determine ORD. In their review, Schmidt et al. (2017) reported that they had found prevalence rates of 5.2–6.4% in two unpublished pilot studies based on a German sample representative of the general population using the ORS-Y-BOCS. To determine ORD, the scale distress was dichotomized into the two groups “clinically significant” vs. “clinically not significant”. A probable diagnosis of ORD was given if a person deviated more than two standard deviations from the distribution average of the scale distress here. However, as far as we know, there is no research on the prevalence of ORD using the newly available, formalized ICD-11 CDDR. For example, resistance and control regarding preoccupation with body odor and repetitive behaviors or distress if the repetitive behaviors are prevented, which are captured in the ORS-Y-BOCS, are not requirements in the ICD-11 while self-consciousness e.g. is an essential feature. Indeed, data on the prevalence of ORD is required to evaluate the respective health burden and treatment needs of ORD sufferers.

Since most patients with ORD initially seek medical help instead of psychiatric treatment due to the belief that they suffer from a physical condition (Greenberg et al., 2016; Phillips & Menard, 2011; Thomas et al., 2015), a non-clinical sample seems crucial for true prevalence estimation. The only two studies indicating that the symptoms of ORD are not uncommon among university students were carried out on Japanese and Chinese university students (Kasahara & Kenji, 1971; Zhou et al., 2018), whereas there are no investigations into the prevalence of ORD in Western cultures. In addition, pressure to perform and fears for the future are common among students and studying is a phase of life that is characterized by many stressors (e.g., a change of friends, a new housing situation after moving out of the parental home, additional burdens due to part-time jobs). Therefore, it is not surprising that mental diseases such as major depression, anxiety disorders or substance use disorders are widespread among students (Auerbach et al., 2018; Blanco et al., 2008). Thus, considering the aforementioned research indicating that ORD might be a relevant disorder among students, we expected that ORD may also be common among our group of German students.

We aimed to assess the point prevalence of ORD in a sample of German university students. To the best of our knowledge, this is the first study to report the prevalence rates of ORD in accordance with the ICD-11. In addition, we assessed the frequency and severity of the single ORD symptoms in the total sample as well as among the participants with a probable ORD diagnosis in order to obtain more empirical data on the diagnostic criteria of the disorder and to contribute to a better understanding of the symptomatology of ORD. Furthermore, we investigated the frequency of students' suicidal thoughts and ideation which we expected to be elevated in participants with ORD, based on previous findings (Phillips & Menard, 2011; Prazeres et al., 2010; Pryse-Phillips, 1971).

## Method

### Sampling and procedure

The data used in this study were collected through an anonymous internet-based survey and administered using the survey tool provided by SoSci Survey (Leiner, 2019). Inclusion criteria were being aged 18 years or older and being a student at a university or college. Participants were recruited by an advertisement placed on the websites of two universities in Germany as well as via campus e-mail newsletters, social media platforms and student chatrooms from the respective university locations and adjoining universities and colleges between December 2021 and May 2022 (until a sufficient sample size was reached). In order to enable the students to make an informed decision about participation, the advertisement contained specific information about the study - such as that the aim of the study is to gain insights into how many people are afraid of having a bad body odor and that the results of the study can help to improve the care of people suffering from such extreme anxiety. In order to increase participation, we provided an incentive by raffling two €500 gift cards for online shopping upon the completion of the survey. The recruitment material presented a link redirecting the students to the survey; the survey took approximately 30 minutes to complete. However, the survey was shortened for participants who did not meet the essential features for ORD. If no symptoms of ORD (score = 0, "not at all") were reported in the first five items of the *Olfactory Reference Disorder Questionnaire* (ORDQ, see 2.2.2; data of the ORDQ was obtained subsequent to the socio-demographic information at the beginning of the survey), the remaining questionnaires were dropped. All participants were informed about all aspects of the study; these aspects included information about the aim, procedure, scope, possible risks of the study and data protection. Participants were informed that they were free to withdraw from the study

at any time without giving reasons and without any prejudice. Informed consent was presented to the participants on a cover page before they started the survey; only if they consented to participate, they were directed to the survey. The study was approved by the ethics committees of the implementing universities.

### Measures

Measures were administered in German.

#### Socio-demographic data

Socio-demographic information comprised age, sex, and relationship status and the level of education. Additional questions concerning bodily diseases that may cause malodor (we assessed hyperhidrosis, trimethylaminuria, gastroesophageal reflux disease, achalasia, irritable bowel syndrome, periodontitis or extreme tooth decay, as well as tumors in the mouth, throat, nose or gullet) were included.

#### Olfactory Reference Disorder Questionnaire (ORDQ)

As there was no existing self-report questionnaire assessing ORD according to ICD-11, we developed the ORDQ for this purpose. In order to evaluate the point prevalence as well as to assess the severity of ORD symptoms, the questionnaire was chosen as the primary outcome measure. The ORDQ is a 16-item self-report measure assessing the core ORD symptom clusters/ essential features (persistent preoccupation, self-consciousness, repetitive and/or avoidance behaviors, distress and/or impairment) over the past three months that must be met to diagnose ORD. While the current version of ICD-11 does not specify a minimum duration or cut-off time to diagnose ORD, we chose this three months period in order to avoid arbitrary diagnoses and to ensure a high reliability. In addition, we assume that one cannot consider "persistent" as being under three months. We decided on this cut-off time after consulting three international experts for ORD, who also considered this period reasonable. In the instruction, respondents were introduced to think about the last three months. Each item is rated on a 5-point Likert scale ("0" = not at all, "1" = a little, "2" = moderate, "3" = severe, "4" = extremely). The first four items of the questionnaire can be used to screen for symptoms of ORD as they assess the essential features of ICD-11 ORD as described above (1: "I am persistently preoccupied about the fact that I emit, or could emit, a foul or offensive body odor or breath," 2: "I am excessively self-conscious about my body odor or breath," 3: "Due to the concern about my body odor or breath, I carry out repeated, excessive behaviors (e.g., I repeatedly check my body odor or repeatedly ask other people about my smell, repeatedly apply perfume or deodorant, I shower

several times a day,...) or avoid (social) situations or activities,” 4: “I suffer from the concern about my body odor or breath or am impaired in my life”). The fifth item assesses the insight into ORD beliefs (“I am absolutely convinced that one or more parts of my body (e.g., mouth, hands, feet, chest, genital area, ...) exude an unpleasant smell, although other people have assured me that this is not the case”). The remaining eleven items ask in-depth questions about the essential features of ICD-11 ORD and can be considered as subitems of the questionnaire. The total score for ORD symptom severity is the sum of the scores for items 1–16, resulting in a score range from 0 to 64. Internal consistency (Cronbach’s alpha) of the total scale for the present sample was 0.92 and for the first four screening items was 0.85.

For the current study, we have added two additional items to the questionnaire assessing symptoms that are not part of the essential features of the ICD-11 ORD, but are often described in the literature as symptoms of ORD (e.g., Feusner et al., 2010; Greenberg et al., 2016). With the first additional item, we assessed shame and fear of rejection due to body odor. The second additional item asked for the avoidance of intimate relationships due to the own body odor.

### Suicidal thoughts and ideation

Suicidal thoughts and ideation were assessed by using item 9 of the German version of the Beck Depression Inventory II (BDI-II) (Hautzinger et al., 2006). This item is rated on a 4-point Likert scale ranging from 0: “I don’t have any thoughts of killing myself” to 3: “I would like to kill myself if I had the chance.” The BDI-II is widely used for the assessment of depression severity in both clinical and non-clinical samples. It has good internal validity and adequate reliability (Kühner et al., 2007), and has been found to be an efficient screen for suicide risk (Green et al., 2015).

### Data analysis

Analyses were run with IBM SPSS version 28 (SPSS Inc., Chicago, USA). The data were analyzed using descriptive statistics and non-parametric Mann–Whitney U-tests. The significance threshold for all analyses was set at  $p < 0.05$ . Missing values were avoided in advance by forced choice format.

## Results

### Sample description

A total of 440 students accessed the survey; of these, 404 participants gave informed consent. The final sample consisted of 275 participants who completed the questionnaires.

The majority ( $n = 216$  [78.5%]) of the participants were female. The mean age was 24.92 years  $\pm$  5.79 (age range = 18–65 years). Table 1 provides a detailed description of the participants’ socio-demographic information.

The analysis of suicidality was based on a sample of only 225 participants from the original 275 (50 cases were excluded due to the complete lack of ORD symptoms being recorded at the beginning of the assessment; see 2.1 for detailed information about the procedure).

### Prevalence of ORD

The presence of the ICD-11 CDDR for ORD was evaluated via the first four screening items of the ORDQ (as described above) as these items assess the four essential features of ORD (persistent preoccupation, self-consciousness, repetitive and/or avoidance behaviors, distress and/or impairment) that are required for a diagnosis outlined in the ICD-11. We considered a symptom as fulfilled if it is stated as “moderate” (as already described, options were “0” = not at all, “1” = a little, “2” = moderate, “3” = severe, “4 = extremely), thus participants with a score greater than or equal to 2 on all four items were considered to have a probable diagnosis of ORD. Five participants were excluded as they reported a medical condition that might account for malodor (three participants named hyperhidrosis and two reported irritable bowel syndrome). The point prevalence (without these five participants) with a cut-off score  $\geq 2$  (“moderate”) for each of the four items was 5.5% (15/275).

**Table 1** Socio-demographic characteristics of the total sample ( $n = 275$ )

	<i>n</i>	%
Gender		
Female	216	78.5
Male	55	20.0
Other (non-binary gender)	4	1.5
Relationship status		
Single	107	38.9
Partnership, living together	60	21.8
Partnership, living apart	89	32.4
Married, living together	15	5.5
Married, living apart	3	1.1
Divorced	1	0.4
Highest educational attainment		
Advanced technical certificate (“Fachabitur”)	19	6.9
Diploma	151	54.9
University degree (e.g., B.A., B.S.)	105	38.2
	<i>M</i>	<i>SD</i>
Age (years)	24.92	5.79

*M* = Mean, *SD* = Standard Deviation

If the five participants were included, there would be a point prevalence of 7.3% (20/275).

None of the participants reached a score  $\geq 3$  (“severe”) on all four screening items. Expanding the criteria to a cut-off score  $\geq 1$  (“a little”) for each of the four items would lead to a prevalence rate of 19.3% (53/275).

### Frequency of single ORD symptoms

We then calculated the frequency of single ORD features with different cut-off scores in the overall sample; these are presented in Table 2. Persistent preoccupation with the belief of malodor and self-consciousness about the perceived odor were the most frequent (in approximately equal frequencies), followed by repetitive and/or avoidance behavior due to malodor concerns, while odor-related suffering and impairment were the least frequent.

### Socio-demographic characteristics of the ORD group

Of the 15 participants who reported at least moderate symptoms in all four essential features of ICD-11 ORD (ORD group), twelve (80%) were female. The mean age of the ORD group was 24.2 years ( $SD=5.36$ , age range: 20–38 years). Eight of the participants were single (53.3%; see Table 3 for a detailed description of socio-demographic characteristics). No differences in age were found for participants with self-reported ORD ( $M=24.2$ ,  $SD=5.36$ ) vs. those participants without self-reported ORD ( $M=24.92$ ,  $SD=5.79$ ) using the non-parametric (two-tailed) Mann–Whitney U-test ( $U=1653.50$ ,  $Z=-0.99$ ,  $p=0.32$ ). Participants of the ORD group reported a mean score of 1.86 ( $SD=6.5$ ) on the entire ORDQ, indicating moderate severity. The mean scores of the first four screening items of the ORDQ for students with self-reported ORD ( $M=2.66$ ,  $SD=0.37$ ) differed significantly from those without self-reported ORD ( $M=0.92$ ,  $SD=0.88$ ) according to the Mann–Whitney U-test ( $U=135.50$ ,  $Z=-6.11$ ,  $p<0.001$ ).

### Descriptive Characteristics of Single ORD Symptoms

Table 4 shows the occurrence frequency of the single ORD symptoms in the ORD group.

**Table 2** Self-reported ICD-11 essential features for ORD in the whole sample ( $n=275$ )

ICD-11 essential feature	score $\geq 1$ : % ( $n$ )	score $\geq 2$ : % ( $n$ )	score $\geq 3$ : % ( $n$ )
Preoccupation about emitting a foul or offensive body odor or breath	69.8 (192)	37.8 (104)	16.0 (44)
Self-consciousness about the perceived odor	63.2 (174)	34.5 (95)	13.8 (38)
Repetitive and/or avoidance behavior	45.5 (125)	24.0 (66)	11.3 (31)
Distress or impairment	26.6 (73)	11.3 (31)	6.2 (17)

**Table 3** Socio-demographic characteristics of the ORD group ( $n=15$ )

	$n$	%
Gender		
Female	12	80.0
Male	2	13.3
Other (Non-binary gender)	1	6.7
Relationship status		
Single	8	53.3
Partnership, living together	3	20.0
Partnership, living apart	2	13.3
Married, living together	2	13.3
Married, living apart	0	0
Divorced	0	0
Highest educational attainment		
Advanced technical certificate (“Fachabitur”)	2	13.3
Diploma	13	86.7
University degree (e.g., B.A., B.S.)	0	0
	$M$	$SD$
Age (years)	24.2	5.36

$M$  = Mean,  $SD$  = Standard Deviation

Symptom “persistent preoccupation:” Of the participants with self-reported ORD, preoccupation with the belief of emitting a foul or offensive body odor was high: seven (46.7%) reported severe preoccupation, two (12.3%) extreme preoccupation, while the remaining six (40%) reported moderate preoccupation.

Symptom cluster “self-consciousness:” Six participants (40%) reported severe self-consciousness on the perceived odor, one (6.7%) reported an extreme level of self-consciousness, while eight (53.3%) participants reported moderate self-consciousness. Nine (53.3%) reported that they were at least severely convinced that one or more parts of their body exuded an unpleasant smell, suggesting poor insight, while four participants (26.7%) rated a moderate conviction. More than half of the participants (60%,  $n=9$ ) reported ideas of reference as being at least a moderate level (of those, four [26.7%] rated this as severe and three [20%] participants had extreme ideas of reference).

Symptom cluster “repetitive and/or avoidance behaviors:” A majority of 13 participants (86.6%) with self-reported

**Table 4** Self-reported symptoms of ORD in the ORD group ( $n = 15$ )

Self-rated criteria	score = 2: % (n)	score = 3: % (n)	score = 4: % (n)
Preoccupation about emitting a foul or offensive body odor or breath	40.0 (6)	46.7 (7)	12.3 (2)
Self-consciousness about the perceived odor	53.3 (8)	40.0 (6)	6.7 (1)
Ideas of reference	60.0 (9)	26.7 (4)	20.0 (3)
Repetitive and/ or avoidance behavior			
Repeatedly checking for body odor/source of smell	20.0 (3)	33.3 (5)	33.3 (5)
Repeatedly seeking reassurance	6.7 (1)	40.0 (6)	0.0
Excessive attempts to camouflage, alter, or prevent the odor	33.3 (5)	46.6 (7)	0.0
Avoidance of body contact or close proximity to other people	20.0 (3)	33.3 (5)	13.3 (2)
Avoidance of social situations	33.3 (5)	20.0 (3)	0.0
Avoidance of social situations/stimuli that increase thoughts about body odor	6.7 (1)	13.3 (2)	0.0
Distress or impairment	53.3 (8)	40.0 (6)	6.7 (1)
Impairment of relationships	26.7 (4)	13.3 (2)	0.0
Problems with family, partner or friends	20.0 (3)	6.7 (1)	0.0
Interference with work, school, university, or ability to work	33.3 (5)	0.0	0.0
Impairment of other important areas of life	13.4 (2)	6.7 (1)	0.0
Additional items			
Feeling shame and fear of being rejected	13.3 (2)	20.0 (3)	46.7 (7)
Avoidance of intimate relationships	26.7 (4)	6.7 (1)	0.0

ORD reported repeatedly checking for body odor or checking the perceived source of the smell (five of each case reported the response as severe or extreme). Seven (46%) reported repeatedly seeking reassurance to at least a moderate level (of these, six [40%] rated their seeking reassurance as severe). Twelve (80%) reported excessive attempts to camouflage, alter, or prevent the perceived odor to at least a moderate extent (seven [46.6%] as strong). Ten (66.6%) reported at least a moderate avoidance of body contact or close proximity to other people (e.g., sitting far away from others), eight (53.3%) participants reported that they avoided social situations to at least a moderate extent due to fear that their body odor would be noticed by other people. However, a majority of twelve participants (80%) reported that they do not, or only a little, avoid social situations or stimuli that increased their own thoughts about their body odor.

Symptom cluster “distress and/or impairment due to ORD symptoms:” Six (40%) reported severe and one participant (6.7%) extreme distress and impairment in their life due to their concerns about their body odor. The remaining eight (53.3%) participants with self-rated ORD reported moderate distress and impairment due to malodor concerns. Six (40%) reported that ORD symptoms at least moderately interfered with their relationships with other people (three [20%] participants gave the response “a little”). Four (26.6%) reported that the symptoms led to problems with their family, partner or friends to at least a moderate extent, while three (20%) gave the response of “a little”. Five (33.3%) reported that their body odor concerns moderately interfered with work, school or university, or their

ability to work (two participants gave the response “a little”), while three (20%) participants were affected in other important areas of life (e.g., hobbies) due to ORD symptoms.

Regarding the two additional items with which we assessed shame and fear of rejection due to body odor as well as avoidance of intimate relationships due to one’s own body odor, the following picture appeared: The majority of participants (80%,  $n = 12$ ) reported that they were ashamed of their body odor and feared being rejected by others because of their smell. Of these, seven (47.7%) rated their feelings of shame and fear of rejection due to their body odor as being extreme. With respect to the avoidance of intimacy, five (33.3%) reported at least a moderate avoidance of intimate relationships due to perceived malodor.

### Suicidal thoughts and ideation

Slightly over half of the participants with self-reported ORD (53.3%,  $n = 8$ ) reported suicidal thoughts (“*I sometimes think of suicide, but wouldn’t do it*”), while one participant stated that she would like to kill herself if she had the chance. Of the participants without self-reported ORD, 16.5% ( $n = 35$ ) reported suicidal thoughts (one of these also reported suicidal ideation). Participants fulfilling self-reported ORD ( $M = 0.73$ ,  $SD = 0.79$ ) and participants without self-reported ORD ( $M = 0.21$ ,  $SD = 0.42$ ) differed significantly in terms of suicidal thoughts and ideation on the suicidality item of the BDI II according to the Mann–Whitney U-test ( $U = 942.00$ ,  $Z = -3.53$ ,  $p < 0.001$ ).

## Discussion

This is the first study exploring the prevalence of ORD measured in accordance with the newly formalized ICD-11 required features, assessed in a non-clinical German university student sample. There are only a few previous studies, which, in the absence of standardized diagnostic categorization, captured the disorder, albeit with different criteria, that reported prevalence rates of 2.1% in a sample of Japanese university students (Kasahara & Kenji, 1971), 2.4% in a sample of Chinese university students (Zhou et al., 2018) and 6.4% in a sample representative of the German general population (Schmidt et al., 2017). Using the ICD-11 CDDR of ORD, we determined a prevalence of 5.5% in our sample. Our findings are consistent with the findings of Schmidt et al. (2017) who suggested that ORD is relatively common in non-clinical settings. Indeed, according to our estimated prevalence of 5.5%, ORD might be more prevalent than other mental disorders in university / college students. For instance, panic disorders or bipolar disorders appear to be less common (12-month prevalence rates of 4.5% and 3.1% respectively are reported; Auerbach et al., 2018). However, based on our results, in university / college student samples ORD seems to be less common than major depression (12-month prevalence of 18.5%; Auerbach et al., 2018), generalized anxiety disorder (12-month prevalence of 16.7%; Auerbach et al., 2018) or alcohol use disorder (12-month prevalence of 6.3%; Auerbach et al., 2018). Similar prevalence rates have been reported for body dysmorphic disorder (prevalence rates of 4.8 to 5.3% have been found; Bohne et al., 2002; Cansever et al., 2003). Given these percentages for other mental disorders, our estimated prevalence of 5.5% indicates that symptoms of ORD are of importance among university students and comparatively frequent.

However, the percentage in our sample is higher than the 2.4% reported in a Chinese Student sample (Zhou et al., 2018), which may be due to the use of other ORD criteria and benchmarks for prevalence counting in the study of Zhou and colleagues (Zhou et al., 2018). In addition, compared to the sample of Zhou et al. (2018) in which about half of the sample consisted of women, our sample consisted mostly (78.5%) of women. This could be due to the fact that women participate in web-based studies more often than men (Gosling et al., 2004). Moreover, research shows that most mental disorders have differential gender prevalence rates (Hartung & Widiger, 1998; Riecher-Rössler, 2017), whereby internalizing mental disorders (i.e., major depression, anxiety disorders, post-traumatic stress disorder) are more common among women than men (Boyd et al., 2015; Seedat et al., 2009; Somers et al., 2006). In the case of obsessive-compulsive

disorder, which can be found in the same ICD-11 section of “Obsessive-Compulsive and Related Disorders” as ORD, the prevalence in women is also increased compared to men (Grabe et al., 2000; Mohammadi et al., 2004). It could, therefore, be that the higher proportion of women in our sample has led to a comparatively higher prevalence. Research so far shows a rather heterogeneous picture with regard to gender differences; in an internet-based survey in an American sample of the general population, Greenberg et al. (2016) found a higher proportion of men with ORD (67%) compared to women (33%) or other (non-binary) gender (0.4%). In clinical samples, some studies show a larger proportion of affected women compared to men (Phillips & Menard, 2011; Schmidt et al., 2021; Sofko et al., 2020), while others have an approximately equal frequency of occurrence among women and men (Prazeres et al., 2010). Future studies are needed to answer the question of gender differences in ORD.

Our findings comply with prior research demonstrating that participants with probable ORD perform time-consuming repetitive and avoidance behaviors (e.g., repeatedly checking for body odor/source of the smell) (Greenberg et al., 2016; Zhou et al., 2018). In addition, similar to previous reports (Greenberg et al., 2016; Phillips & Menard, 2011; Schmidt et al., 2022), our study shows that the disorder goes hand in hand with feelings of shame and anxiety of rejection, and severely impairs social life. For example, more than half of the participants with self-reported ORD reported at least a moderate avoidance of body contact or close proximity to other people as well as avoidance of social situations. Interestingly, a majority of 80% of participants who met self-rated features for ORD reported that they do not, or only a little, avoid social situations or stimuli that increase their own *thoughts* about body odor. This symptomatology seems to be similar to social phobia in which those affected endure and get through the dreaded social situations under great fear if the situation cannot be avoided (American Psychiatric Association, 2013). However, future research is needed to investigate this hypothesis. Moreover, it is possible that our sample of university students has overestimated this result in that our participants are in a phase of life in which they are constantly confronted with interpersonal situations (e.g., contacts with fellow students during attendance at seminars or lectures) that cannot be avoided persistently.

With respect to the diagnosis of ORD, our finding points to a challenge to researchers applying the ICD-11 definition of the disorder. The ICD-11 uses an approach with a simplified diagnostic structure to increase clinical utility (Reed et al., 2019). Cut-offs or requirements regarding the number and duration of symptoms to make a diagnosis are generally dropped (Reed et al., 2019). In the clinical setting this approach brings about the advantage of a flexible application

of clinical judgment (Reed et al., 2019). In research, however, the lack of specification can be problematic. With regard to the CDDR of the ORD, there is no clarity on what “persistent” means in the ICD-11 definition. Other formulations such as “excessive” or “time-consuming” are also open for interpretation because it is not clear what exactly they imply.

Our findings indicate that single symptoms of ORD are frequent even without a diagnosis of ORD. The core symptom of persistent preoccupation with the belief that one is emitting a foul or offensive body odor or breath was most frequently reported. Distress and impairment linked to these ORD symptoms was relatively high (11% with a “moderate” score) which indicates that, even without a diagnosis, these single symptoms may cause suffering and impairment.

This in turn points to the necessity to specify the diagnostic definition of the disorder, at least with respect to the research context, in order to distinguish between subclinical symptoms and a clinically relevant condition. In our view, there should be a consensus from which a feature is assumed to apply. Without such cut-offs there may be a decrease in diagnostic reliability because features labeled as “persistent” will be interpreted differently depending on the researchers. Such a specification of the symptoms, for how long and in what form these symptoms must be present in order to meet the diagnosis, will probably also have an impact on the prevalence of the disorder. In the present study, we decided, after consultation with international experts, on a three-month history as the minimum duration of the features. Future epidemiological research is needed to help determine the optimal time cut-offs.

Consistent with the existing research (e.g., Greenberg et al., 2016; Phillips & Menard, 2011), we found an increased prevalence of ideas of reference among participants with probable ORD. Specifically, more than half of the participants with self-rated ORD (60%) reported to at least a moderate level, that they attribute various actions of other individuals (e.g., scrunching of one’s nose, turning away, opening of windows, etc.) as either a direct consequence of themselves or their own smell.

The fact that, in the current study, the vast majority (80%) of the participants with probable ORD reported poor insight to at least a moderate extent (of whom, 53.3% were at least strongly convinced that their beliefs were true) is in line with previous findings reporting percentages of 57–90% of poor insight among individuals with ORD both in clinical and non-clinical settings (Begum & McKenna, 2011; Phillips & Menard, 2011; Zhou et al., 2018). The high number of participants with poor insight shows similarities to body dysmorphic disorder (Phillips et al., 2012; Toh et al., 2017) but not to obsessive-compulsive disorder (OCD). Those affected by OCD are usually aware of the exaggeration and senselessness of their compulsions (Eisen et al., 2004;

Schulte et al., 2020), while this does not seem to be the case with the majority of those affected by ORD. These findings underscore the importance of future studies that compare the insights in ORD and OCD. However, results of the present study show a range of different insight levels, suggesting that ORD is not a delusional disorder since the symptoms are not always accompanied by delusional convictions. Our findings parallel prior research (Begum & McKenna, 2011; Greenberg et al., 2016; Phillips & Menard, 2011) and are consistent with the ICD-11 CDDR which distinguish between good and poor insight into disorder-specific assumptions.

The findings regarding suicidality also correspond with previous research results (Begum & McKenna, 2011; Feusner et al., 2010; Greenberg et al., 2016; Phillips & Menard, 2011; Prazeres et al., 2010; Pryse-Phillips, 1971). As expected, our data indicates that ORD causes high suffering and impairment, and is frequently accompanied by suicidal thoughts. Thus, our findings emphasize the importance to record, routinely, suicidality in the clinical setting in ORD and underline the need for treatment of ORD sufferers. Clearly, due to our cross-sectional design, we are not able to determine a causal relationship between olfactory concerns and suicidal thoughts. Moreover, we did not test whether other conditions such as depression or anxiety disorders could have influenced our findings on suicidality. Finally, 50 participants who did not report any symptoms of ORD at the beginning of the survey did not answer the item regarding suicidal thoughts and ideation (see 2.1). The exclusion of such participants skews the dataset and leads to a significant limitation of our results regarding suicidality.

There are several other limitations that need to be acknowledged. In our study, participants who scored  $\geq 2$  (moderate) on the first four items of the ORDQ were considered to have clinically significant ORD symptoms. Our criteria were very close to the definition of the ICD-11 since these four items basically represent a 1:1 translation of the required features proposed in the ICD-11. Therefore, the diagnosis of an ORD according to the ICD-11 is justified once all four items are met. However, a shortcoming of the present study is that due to non-existent evaluated measuring instruments with defined cut-offs, we had to evaluate, categorically, a dimensional scale. Furthermore, although the internal consistency of the ORDQ was good (for the four screening items) to excellent (total scale), the psychometry of the instrument still needs to be evaluated. Future studies using evaluated, psychometrically sound and reliable measuring instruments are needed to confirm our results on prevalence. Another limitation in this study was our reliance on self-rating scales. In the absence of structured in-person interviews, the diagnosis of an ORD was not confirmed. For example, it was not possible to objectify whether there was not only a participant-perceived but also an actual body odor or whether comorbid



psychopathology may have influenced or explained the results. Moreover, we excluded participants with hyperhidrosis or irritable bowel syndrome as these medical conditions may have been accounted for malodour. However, it could be that, for example, in the case of self-reported hyperhidrosis, a diagnosis of ORD is (also) present. Thus, the affected person perceives one's own sweat production as excessive due to fears of body odor. In these cases, the prevalence in our sample would be higher than 5.5%, namely 7.3%. Nonetheless, the use of low-threshold access via an anonymous online survey seems favorable given that ORD is accompanied by much shame (Pryse-Phillips, 1971; Stein et al., 1998). Those affected do not necessarily reveal their fears in a personal contact, which could, therefore, lead to an underestimation of the prevalence. Through anonymous self-rating, it is possible to obtain a wider range of symptoms and insight. Finally, our study was advertised with the actual study objective; participants were fully informed about the aim of the study, which means a sampling bias cannot be ruled out. Our findings require confirmation in future studies in which the purpose of the investigation is concealed (for instance, by using a cover story). Beyond that, our results are based on a relatively homogeneous, specific and rather small sample consisting of German university students who were predominantly female. In particular, the group of participants with self-reported ORD is small. This limits the generalizability of the present results to other populations. Future studies with different, large and more diverse samples are necessary to confirm our results. Moreover, future research is required to assess the prevalence of ORD in the general population.

## Conclusions

To our knowledge, this is the first study on the prevalence of ICD-11 ORD. About 5.5% of our sample reported clinically significant ORD symptoms. This finding suggests that ORD may be comparatively common among university students compared to other mental disorders. Moreover, our results indicate that single symptoms of ORD frequently occur in student samples and cause impairment. Our findings provide new information about the epidemiology of the disorder which is understudied in research worldwide and indicates the need for further research in order to be able to provide suitable treatment to those affected.

**Abbreviations** *BDI-II*: Beck Depression Inventory II; *CDDR*: Clinical Descriptions and Diagnostic Requirements; *DSM-5*: Diagnostic and Statistical Manual of Mental Disorders (5th edition); *ICD-11*: International Classification of Diseases (11th revision); *M*: Mean;

*OCD*: Obsessive-compulsive disorder; *ORD*: Olfactory Reference Disorder; *ORDQ*: Olfactory Reference Disorder Questionnaire; *SD*: Standard Deviation

**Acknowledgments** We thank Prof. Dr. David Veale, Prof. Dr. Dan Stein and Dr. Karen Mare for their feedback regarding the minimum duration of criteria to diagnose ORD.

**Authors' contributions** Julia Reuter: Conceptualisation, Methodology, Software, Formal analysis, Investigation, Data curation, Writing - Original draft, Writing - Review & Editing. Anja Grochowski: Conceptualisation, Methodology, Writing - Review & Editing. Regina Steil: Conceptualisation, Methodology, Writing - Review & Editing. All authors read and approved the final manuscript.

**Funding** Open Access funding enabled and organized by Projekt DEAL. The authors did not receive support from any organization for the submitted work.

**Data availability** The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

## Declarations

**Ethics approval and consent to participate** The study was approved by the ethics committee of the Medical Faculty of Goethe-University Frankfurt, Germany and by the ethics committee of Technische Universität Braunschweig, Germany. The study was in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

**Consent to participate** Online informed consent was obtained from all individual participants included in the study.

**Consent for publication** Not applicable.

**Competing interests** The authors have no competing interests to declare that are relevant to the content of this article. Anja Grochowski is the clinical director of the special outpatient clinic at the Technische Universität Braunschweig for body dysmorphic and related disorders, in which ORD is also treated and researched.

**Conflict of interests** On behalf of all authors, the corresponding author states that there is no conflict of interest.

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