

# Oftentimes overlooked?! The Body Dysmorphic Disorder and the Olfactory Reference Disorder

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## Abstract

Appearance and body odour are important issues these days and people are increasingly investing in them (e.g. through cosmetic-medical treatments, or the use of perfume). A severe investment in appearance or smell is not psychopathologically conspicuous per se, but it could provide evidence of associated mental disorders: the body dysmorphic disorder (appearance) or the olfactory reference disorder (smell). Both disorders are underrepresented in both research and clinical practice and are presented in the article. The point prevalence of body dysmorphic disorder in the German general population is slightly more than 2%. The disorder begins in adolescence, is usually chronic if left untreated, and can lead to increased suicide rates and social isolation. Those affected seek primarily non-psychiatric/psychotherapeutic treatment settings and only come to psychiatric/psychotherapeutic treatment at a late stage. Cognitive behavioural therapy and selective serotonin reuptake inhibitors have proven to be particularly effective for treatment, and treatment manuals in German have now been published. Reliable estimates of the prevalence of the olfactory reference disorder are not yet available. The disorder probably begins in young adulthood. There is a tendency towards chronicity with increased suicide rates and severe impairments in social and professional life. Here too, those affected initially seek non-psychiatric/psychotherapeutic treatment. The effectiveness of psychotherapy and/or pharmacotherapy has so far only been demonstrated in individual case studies; no reliable statements can be made here.

**Key words:** body dysmorphic disorder, dysmorphophobia, olfactory reference disorder, olfactory reference syndrome

## Häufig übersehen?!

### Die Körperdysmorphie Störung und die Olfaktorische Referenzstörung

#### Zusammenfassung

Das Aussehen und der Körpergeruch sind heutzutage wichtige Themen, und Menschen investieren zunehmend in sie (z.B. durch kosmetisch-medizinische Behandlungsmaßnahmen oder den Gebrauch von Parfüm). Eine starke Investition in Aussehen oder Geruch ist nicht per se psychopathologisch auffällig, könnte aber Hinweise geben auf assoziierte psychische Störungen: die Körperdysmorphie Störung (Aussehen) oder die Olfaktorische Referenzstörung (Geruch). Beide Störungen sind sowohl in Forschung als auch klinischer Praxis unterrepräsentiert und werden im Beitrag vorgestellt. Die Punktprävalenz der Körperdysmorphie Störung in der deutschen Allgemeinbevölkerung liegt bei etwas mehr als 2%. Die Störung beginnt in der Adoleszenz, verläuft unbehandelt in der Regel chronisch und kann zu erhöhten Suizidraten und sozialer Isolation führen. Betroffene suchen primär nicht-psychiatrische/psychotherapeutische Behandlungsssettings auf und kommen erst spät in psychiatrische/psychotherapeutische Behandlung. Zur Behandlung haben sich besonders die Kognitive Verhaltenstherapie und Selektive Serotonin Wiederaufnahmehemmer als wirksam erwiesen, es existieren mittlerweile deutschsprachige Behandlungsmanuale. Über die Olfaktorische Referenzstörung liegen noch keine zuverlässigen Prävalenzschätzungen vor. Vermutlich beginnt die Störung im jungen Erwachsenenalter. Es zeigt sich ein zur Chronifizierung neigender Verlauf mit erhöhten Suizidraten und starken Beeinträchtigungen im sozialen und beruflichen Leben. Auch hier suchen Betroffene zunächst nicht-psychiatrische/psychotherapeutische Behandlung auf. Die Wirksamkeit von Psychotherapie und/oder Pharmakotherapie wurde bisher nur in Einzelfallstudien nachgewiesen; hier sind keine gesicherten Aussagen möglich.

**Schlüsselwörter:** Körperdysmorphie Störung, Dysmorphophobie, Olfaktorische Referenzstörung, Olfaktorisches Referenzsyndrom

## Introduction

The importance of physical appearance is important. Among other things, this is reflected in the fact that the rate of cosmetic-medical treatments is constantly increasing; extrapolating the statistics of the International Society of Aesthetic Plastic Surgery (ISAPS) from 2010 to 2018, by 164,9% (ISAPS, 2020). In the country ranking of the 10 nations with the most surgical and non-surgical treatments, the Federal Republic of Germany was in fourth place in 2018 (ISAPS, 2020). However, a high investment in appearance through the above-mentioned measures does not necessarily have to be regarded as a symptom of psychopathology: the majority of patients who want cosmetic-medical treatment do not have any mental disorders (Sarwer, Crerand, & Didier, 2003). On the contrary, in a study of 544 people who underwent aesthetic surgery (compared to 264 people who wanted such an operation but did not have it) it was found that in those who underwent the treatment, the procedure apparently resulted in positive, self-reported psychological changes – even one year after the procedure (Margraf, Meyer, & Lavallee, 2013).

But not only the appearance counts – body odour is also important. A person's intrinsic odour fulfils various useful purposes. For example, it is important for sympathy and attachment (Croy, Frackowiak, Hummel, & Sorokowska, 2017), for the choice of the sexual partner (Martins, Preti, Crabtree, Runyan, Vainius, & Wysocki, 2005) and warns the organism of diseases (Olsson et al., 2014). Body odours can also cause disgust, probably one of the reasons why people try to avoid or cover up body odours (Herz, 2001). In March 2018, SPLENDID RESEARCH GmbH conducted an online survey of 1,016 people in the age group from 18 to 69 years (SPLENDID RESEARCH, 2018). In response to the question: "How often do you use perfume/ eau de toilette/ eau de cologne yourself?", 44% said that they use these products daily or almost daily, 27% several times a week, 12% weekly or several times a month – only 8% reported never using these products (SPLENDID RESEARCH, 2018). The survey shows that people not only invest in their appearance, but also in their smell. Unfortunately, there are no findings as to whether a high investment in one's intrinsic odour can (or cannot) be related to a psychopathology.

Even if the appearance and the own smell are important for people, and at least an investment in the appearance through cosmetic-medical measures does not at first glance provide evidence of a possible psychopathology, high demand behaviour or high (mental) preoccupation with appearance or odour can nevertheless assume clinically relevant dimensions. One of the disorders strongly associated with appearance-related concerns (besides eating disorders) is body dysmorphic disorder (BDD); a disorder associated with odour-related concerns is

olfactory reference disorder (ORD). Both are clearly underrepresented and underdiagnosed in both research and practice compared to other disorders. In the following article, the two disorders are presented and similarities and differences are shown.

## 1 Body dysmorphic disorder (BDD)

### 1.1 Phenomenology and epidemiology of BDD

The BDD is characterized by concerns about one or more flaws in the appearance of the patient, with little or no external visibility (Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> version [DSM-5]; American Psychiatric Association APA, 2013). In the case of clearly recognizable physical disfigurements (i.e. those that are not just minor), the diagnosis should not be made (APA, 2013). Most commonly, flaws are felt in the face or head area (e.g. bad skin, a crooked nose or asymmetrical eyes) (Phillips, McElroy, Keck, Pope & Hudson, 1993). Most sufferers also worry about several blemishes at once (Phillips, Grant, Siniscalchi, Stout, & Price, 2005). Often, those affected are so strongly convinced that the distorted perception of their appearance corresponds to reality that the beliefs about their appearance appear delusional (e.g. Hartmann, Thomas, Wilson, & Wilhelm, 2013). Some sufferers also show ideas of reference, which means, that they are convinced that others would talk negatively about them or laugh at them because of their appearance (Hartmann, Grocholewski & Buhlmann, 2019; Phillips, 2004).

Another characteristic are repetitive ways of thinking and behaving (APA, 2013). Because of the conviction that they are ugly or disfigured by the blemishes, a large number of those affected try to check, change or bring the flaw under control (e.g. Phillips et al., 2005), i.e. they show certain safety behaviours. A very common safety behaviour is checking the appearance in a mirror or other reflective surfaces such as shop windows (e.g. Phillips, 2005; Veale & Riley, 2001), other safety behaviours are covering up the flaws (e.g. wearing sunglasses if there is a fear of dark circles under the eyes) and excessive combing, applying make-up, skin manipulation (e.g. squeezing out pimples) or constantly asking other people about their appearance (Hartmann et al., 2019). There is an affinity for cosmetic-medical treatments: in a representative German-wide survey, significantly more people with BDD than non-affected people reported a history of aesthetic surgery (15,6% vs. 3%; Buhlmann et al., 2010). But there are also mental actions, such as comparing one's perceived blemishes with the corresponding body regions of other people (Hartmann et al., 2019; Phillips, 2005). Besides safety behaviour, avoidance also plays an important role at

BDD. Avoidance can concern mirrors (or reflective surfaces) to avoid negative feelings that can be caused by exposure to one's own reflection, as well as everyday activities such as shopping, if there is a risk of exposing the perceived blemishes to the public (Phillips et al., 1994). Safety and avoidance behaviour can go so far that those affected are completely tied to the house because they no longer dare to enter social situations and because the safety behaviour takes up too much of their time (Phillips, Menard, Fay, & Weisberg, 2005). Those affected report a low self-esteem (Buhlmann, Wilhelm, Glaesmer, Brähler, & Rief, 2009; Hartmann et al., 2015) and show a significantly reduced quality of life, even in comparison with people with clinically relevant depressive disorders (Phillips & Menard, 2006). Another prominent feature of BDD is social anxiety. Both cross-sectional and prospective, a higher level of social anxiety is associated with a lower level of psychosocial functioning (Kelly, Walters, & Phillips, 2010). In a study that compared those affected by BDD with people with social phobia, it was found that the two disorders did not differ significantly in their social anxiety in performance situations but that those with social phobia had higher social interaction anxieties (Grocholewski, Kliem & Heinrichs, 2013). High rates of suicidal thoughts and attempts are found among BDD sufferers. Phillips, Menard, Fay and Weisberg (2005) found in an investigation of 200 BDD patients that 109 people (81,3%) had ever thought of suicide and 38 people (28,4%) had attempted suicide at least once (Phillips et al., 2006). In two Germany-wide, representative surveys, Rief et al. (2006) and Buhlmann et al. (2010) linked suicidal tendencies with appearance-related fears. In these studies, 19,1% (2006) and 31% (2010) of those affected by BDD (compared to those not affected, where the rates were 3,4% and 3,5% respectively) reported that they currently have suicidal thoughts because of their appearance; a total of 7,2% (2006) and 22,2% (2010) of those affected by BDD stated that they had attempted suicide at least once because of their appearance (versus 1% and 2,1% of those not affected) (Rief, Buhlmann, Wilhelm, Borkenhagen, & Brähler, 2006; Buhlmann et al., 2010).

Epidemiological studies from the USA (Koran, Aboujaoude, Large, & Serpe, 2008) and Sweden (Brohede, Wingren, Wijma, & Wijma, 2015) found a point prevalence in the general population of 2,4% and 2,1%, respectively. In the representative studies by Rief et al. (2006) and Buhlmann et al. (2010) mentioned above, point prevalences of 1,7% and 1,8% were found for Germany. A more recent, also representative German study which measured point prevalence according to both DSM-IV and DSM-5 (changed criteria in DSM-5, see below), found a point prevalence of 3,2% in the general population according to DSM-IV- and 2,9% according to DSM-5 criteria (Schieber, Kollei, de Zwaan & Martin, 2015). There are higher prevalence rates in certain

contexts. In the systematic review by Veale et al. (2016), weighted prevalence rates were calculated for different samples: here the weighted prevalence in the adult general population was 1,9%, in adolescents 2,2% and in students 3,3% (Veale, Gledhill, Christodoulou, & Hodsoll, 2016). Prevalences of 7,4% were found in adolescent and adult inpatient psychiatric patients, and 5,8% in adult outpatients (Veale et al., 2016). As expected, there are also higher prevalence rates in the setting of cosmetic medical treatments. The most recent review with meta-analysis by Ribeiro (2017) found 23 publications with prevalence data on BDD in plastic surgery and 10 on BDD in dermatology (Ribeiro, 2017). A frequency of 15% was found for the plastic-surgical setting (range = 2.21%–56.67%), and 12,7% for the dermatological setting (range = 4.52%–35.16%) (Ribeiro, 2017). With regard to gender, there is an approximately equal distribution with a slight excess of women (Hartmann et al., 2019). However, clear gender differences can be found in the body regions in focus: While men are more likely to worry about their genitals, stature and hair loss, women are more concerned about their skin, abdomen, weight, chest, bottom, hips, legs, toes and body- and facial hair (Hartmann et al., 2019). In general, women also seem to worry about more areas of their body than men (Phillips, Menard, & Fay, 2006).

On average, the disorder begins at around 16 years of age (Coles et al., 2006; Fang & Wilhelm, 2013), but the mode seems to be rather around 12-13 years (Bjornsson, Didie, Grant, Menard, Stalker, & Phillips, 2013; Fang & Wilhelm, 2013). A prospective four-year study in adolescents and adults with BDD showed that the disorder is typically chronic, with a probability of (only) 20% of full remission and a high probability of relapse (42%) (Phillips, Menard, Quinn, Didie, & Stout, 2013).

## 1.2 Classification of the BDD

Even though BDD symptomatology have been described in the literature for more than 100 years, BDD as a distinct disorder was only included in the classification systems with the revision of the DSM-III, under the chapter on somatoform disorders (APA, 1987). Since then, the term "body dysmorphic disorder" has also been used. In DSM-IV, too, BDD continued to be subsumed under somatoform disorder, the required diagnostic criteria were: "A. Preoccupation with an imagined defect in appearance. If a slight physical anomaly is present, the person's concern is markedly excessive., B. The preoccupation causes clinically significant distress or impairment in social, occupational, or other important areas of functioning C. The preoccupation is not better accounted for by another mental disorder (e.g., dissatisfaction with body shape and size in anorexia nervosa) (APA, 1994). A major change resulted from the introduction of the DSM-5. One innova-

tion is that BDD is now subsumed under the chapter "Obsessive-Compulsive and Related Disorders", i.e. a conceptual change has taken place (APA, 2013). This was partly due to the similarity in phenomenology, epidemiology and effective treatment strategies with obsessive-compulsive disorder (Hartmann et al., 2019). As a result, the diagnostic criteria have also changed slightly or a "obsessive-compulsive criterion" has been added: "[. . .] B. At some point during the course of the disorder, the individual has performed repetitive behaviors (e.g., mirror checking, excessive grooming, skin picking, reassurance seeking) or mental acts (e.g., comparing his or her appearance with that of others) in response to the appearance concerns. [...]" (APA, 2013).

In the International Statistical Classification of Diseases and Related Health Problems (ICD) the BDD has only been included in the 10th version, where it is currently classified as a sub-form of hypochondria in the chapter on somatoform disorders under the heading "dysmorphophobia (not delusional)" (F45.22; WHO, 1992). In the case that beliefs about the appearance-related concerns appear delusional, the disorder can be coded as other persistent delusional disorder (F22.8 - delusional dysmorphophobia) according to ICD-10. With the revision of the ICD, the BDD will also find a place in the ICD-11 in the future (analogous to DMS-5), subsumed under obsessive-compulsive or related disorders (WHO, 2019), where the term "body dysmorphic disorder" will now also be adopted. In addition to DSM-5 criteria, which have been adopted analogously, two further important aspects are now included in the definition: "Individuals experience excessive self-consciousness, often with ideas of reference (i.e., the conviction that people are taking notice, judging, or talking about the perceived defect or flaw)" and additionally according to the obsessive-compulsive criterion "[...] or marked avoidance of social situations or triggers that increase distress about the perceived defect or flaw" (WHO, 2019).

### 1.3 Differential diagnosis and comorbidities of BDD

A differential diagnostic differentiation of BDD from obsessive-compulsive, social anxiety, eating and depressive disorders is urgently needed (Hartmann et al., 2019). With the obsessive-compulsive disorder the BDD connects in particular the intrusive thoughts and the repetitive behaviours, here attention must be paid to the content of the intrusive thoughts for differentiation (is a ritual performed to influence the appearance or, for example, to counteract contamination) (Hartmann et al., 2019). With the social anxiety disorder, the BDD connects the fear of and avoidance of social situations due to the fear of negative evaluation and re-

jection – here, too, the focus must be placed on the content of the fears in order to differentiate (evaluation anxiety due to appearance versus due to behaviour) (Hartmann et al., 2019). In the case of social anxiety disorder, compulsive behaviour does not occur regularly (Fang & Hofmann, 2010). The connection to the eating disorders is due to the high degree of dissatisfaction with the body and a negative and distorted body image. In addition, repetitive behaviours such as checking one's appearance in the mirror or hiding the body is found in both disorders (e.g. Hartmann, Thomas, Greenberg Elliott, Matheny, & Wilhelm, 2015). In eating disorders, however, fears are primarily related to weight and body shape, whereas fears in BDD can affect the whole body, but usually relate to the face/ head (Hartmann et al., 2019). In the BDD subtype of muscle dysmorphia (people who fear that they are too narrow or not sufficiently muscular) there is often a diet behaviour that is similar in its rigidity to the diet behaviour of anorexia nervosa (Chung, 2001; Murray, Rieger, Touyz, & de la Garcia Garcia, 2010), but unlike eating disorders, this is not about losing weight. Depressive disorders share with BDD low self-esteem, fear of rejection and feelings of worthlessness (APA, 2013). However, in the case of depressive disorders, no underlying compulsive thoughts and behaviours can be found (Hartmann et al., 2019).

The above-mentioned differential diagnoses can often also be found as comorbid disorders: the most common are depressive disorders (point prevalence 8%–69%, lifetime prevalence 41%–82%), social anxiety disorders (point prevalence 16%–69%, lifetime prevalence 12%–54%), obsessive-compulsive disorder (point prevalence 6%–38%, lifetime prevalence 14%–78%), eating disorders, especially anorexia nervosa (point prevalence 4%–19%, lifetime prevalence 4%–22%) and substance abuse/dependence (point prevalence 2%–17%, lifetime prevalence 30%–36%) (Veale & Neziroglu, 2010). Comorbid personality disorders occur in 39% of those affected over the course of their lives, especially from cluster C (avoidant, dependent, and compulsive personality disorder) (e.g. Ruffolo, Phillips, Menard, Fay, & Weisberg, 2006).

### 1.4 Treatment of BDD

People with BDD usually come to psychiatric/ psychotherapeutic treatment late. One reason for this is that people with BDD often prefer non-psychological/ non-psychiatric treatments (e.g. cosmetic or dermatological treatments and aesthetic plastic surgery) instead of disorder-specific specialist treatments because they want to change the blemishes directly. Unfortunately, these treatments usually do not lead to a decrease, but rather to an increase in the symptomatology (e.g. Crerand, Phillips, Menard, & Fay, 2005). On the other hand, those

affected often report that they are ashamed of their fears about their appearance and therefore do not seek psychotherapeutic or psychiatric treatment (Buhlmann, 2011). As a result, there are often concrete difficulties in the initial consultation or in the first phase of therapy (e.g. lack of insight into the disease and lack of motivation, often also the desire for appearance-changing measures as well as feelings of shame that make it difficult for the patient to open up to himself) (Hartmann et al., 2019). However, these difficulties can be countered well with established psychotherapeutic standard interventions, e.g. Motivational Interviewing (Miller & Rollnick, 2013) to deal with ambivalent or limited therapy motivation (Hartmann et al., 2019).

According to the current state of research, both cognitive behavioural therapy and drug therapies with selective serotonin reuptake inhibitors (SSRIs) have proven to be effective (e.g. Williams, Hadjistavropoulos, & Sharpe, 2006; Ipser, Sander, & Stein, 2009; Fang & Wilhelm, 2015; Harrison, Fernandez de la Cruz, Enander, Radua, & Mataix-Cols, 2016). Overall, the current state of research provides promising evidence for the effectiveness of cognitive-behavioural therapies in the treatment of BDD, both in terms of body dysmorphic and depressive concomitant symptoms (Hartmann et al., 2019). German language CBT manuals are now also available (Hartmann et al., 2019; Brunhoeber, 2019).

There are now a large number of studies that have examined the effectiveness of psychopharmacological treatments for BDD, especially SSRIs have proven to be effective (Williams et al., 2006). It has been shown that taking SSRIs can reduce both the severity of BDD symptoms as well as the associated burden and the degree of belief in appearance-related assumptions (e.g. Phillips, Pagano, & Menard, 2006; Phillips & Hollander, 2008). The effectiveness of an SSRI depends, on the one hand, on the fact that, on average, the drug dose must be significantly higher than in depression treatment (similar to obsessive-compulsive disorder), e.g. the average daily dose of citalopram for people with BDD is 66 mg (standard deviation 36 m) (Phillips, 2005). On the other hand, it is important to remember that the effect of the drug on people with BDD (compared to depressed people) only takes effect later; the effect should be observed over a period of 12 to 16 weeks before alternatives are considered (e.g. Phillips, Albertini, & Rasmussen, 2002; Phillips, 2005). Relapses can be reduced by the use of escitalopram (compare to a placebo condition) six months beyond the acute phase (Phillips, Keshaviah, Dougherty, Stout, Menard, & Wilhelm, 2016). Controlled therapy studies comparing different approaches (e.g. CBT) vs. SSRIs are currently still pending (Hartmann et al., 2019).

## 2 Olfactory Reference Disorder (ORD)

### 2.1 Phenomenology and epidemiology of ORD

The ORD is characterized by worries about an unpleasant intrinsic odour that is emitted but this odour is not or hardly smelled by others (Greenberg, Shaw, Reumann, Schwartz, & Wilhelm, 2016; Phillips & Menard, 2011). If an odour is actually present, the concern is clearly disproportional to the intrinsic odour (Stein et al., 2016), so that it can be concluded that the diagnosis should not be made if the inherent odour is clearly recognisable. ORD is also primarily not present if there is a physical cause for a strong inherent odour (e.g. mouth infection) (Lochner, 2003). A detailed German-language review on olfactory reference disorder including casuistry was published in 2017 (Schmidt, Haiduk & Grocholewski, 2017). The parts of the body that are said to emit the smell are mainly the armpits, the genital area, the feet and the mouth (Greenberg et al., 2016; Phillips & Menard, 2011, Begum & McKenna, 2011). However, it is sometimes said that the whole body emits an odour (Bishop, 1980). The most common fears relate to smelling of sweat, faeces, ammonia or to have bad breath (Greenberg et al., 2016; Phillips & Menard, 2011). Similar to BDD, ORD sufferers are so convinced that the feared smell corresponds to reality that the concerns about the smell may appear delusional (e.g. Pryse-Phillips, 1971; Schmidt et al., 2017). Phillips and Menard (2011) found in their study of 20 participants with ORD that 84,6% of the participants were completely convinced of the assumption that they smelled bad and only 7% showed at least moderate insight into the exaggeration of their fears (Phillips & Menard, 2011). In a review from 2011 comparing 84 individual case reports (52 male, 32 female), the authors found a lack of insight in 57% of the cases (Begum & McKenna, 2011). In the online study by Greenberg et al. (2016), which is currently the study with the largest sample of 253 people affected, only 18% showed little or no insight (Greenberg et al., 2016). Ideas of reference are also quite common among sufferers, e.g. in the form that they think that if someone opens the window, it is because of their smell (Schmidt et al., 2017). Begum and McKenna (2011) found frequencies for ideas of references between 62%–84%, Greenberg et al. (2016) 64,2% (Begum & McKenna, 2011; Greenberg et al., 2016). In case reports it is often also described that those affected not only fear an inherent odour, but actually smell it – i.e. seem to have olfactory hallucinations (e.g. Bizamcer, Dubin, & Hayburn, 2008; Jegede et al., 2018). Greenberg et al. (2016) found 59,3% of the patients they examined who would actually perceive the feared smell (Greenberg et al., 2016). In the review by Be-

gum and McKenna, a rate of 22% is mentioned (Begum & McKenna, 2011).

Another core characteristic of ORD sufferer are repetitive behaviours to remove or mask the feared odour (e.g. Phillips & Menard, 2011; Schmidt et al., 2017), i.e. certain specific safety behaviours are applied. Greenberg et al. (2016) state that 99,6% of their participants stated that they performed coercive rituals (Greenberg et al., 2016). This often involves showering, changing clothes several times or (excessive) use of deodorant or perfume (e.g. Greenberg et al., 2016; Schmidt et al., 2017). Even sniffing the affected body regions to check if they smell or reinsurance from other people is also common (e.g., Greenberg et al., 2016; Schmidt et al., 2017). Avoidance behaviour can also be observed as a rule, especially in social situations or at work, where those affected fear their body odour could be perceived by others (e.g. Greenberg et al., 2016; Schmidt et al., 2017). Greenberg et al. (2016) mention avoidance behaviour in 99,2% of the sample, for example, those affected sit further away from others or change sides of the street (Greenberg et al., 2016). The psychosocial effects of ORD can also be assessed as profound: 56% of respondents reported that odour-related fears were one of their biggest or even biggest problems for them (Greenberg et al., 2016). Due to their fears, the participants stated significant limitations in social functioning and at work (Greenberg et al., 2016). For the survey, the authors use the Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002), the mean value of the WSAS was 26.88 ( $SD = 7,72$ ) for ORD patients, and was thus higher than the mean values reported in the literature for depressed patients ( $M = 24,8$ ,  $SD = 7,3$ ) or obsessive-compulsive disorder patients ( $M = 20,4$ ,  $SD = 7,7$ ) (Greenberg et al., 2016). In the study by Phillips and Menard (2011), 40% of those affected felt unable to leave the house for at least a week due to ORD symptoms (Phillips & Menard, 2011). Prazeres et al. (2010) report that 64,3% of ORD sufferers have suicidal thoughts and 21,4% have attempted suicide (Prazeres, et al., 2010). Pryse-Phillips (1971), who first empirically investigated ORD, found that 43% of people with ORD had suicidal thoughts or attempts (Pryse-Phillips, 1971).

Only three studies have investigated how often the disorder occurs. A study in Great Britain investigated ORD symptoms in patients in a London hospital and found a point prevalence of 0,5% (Marks & Mishan, 1988). In a survey of Japanese students, the point prevalence was 2,1% (Kasahara & Kenji, 1971). A recent Chinese study found a point prevalence of around 2% among Chinese students (Zhou, Schneider, Cepeda, & Storch, 2018). Two own online surveys as part of Bachelor theses ( $N = 173$  and  $N = 309$ ) showed point prevalences of 6,4% and 6,5% respectively (Gerlach, 2013; Spanger, 2016). The operationalisation of these two studies must be critically discussed (including the format

of the online survey, which queries symptoms but does not allow clinical diagnoses), so that it can be assumed that the point prevalences of the two bachelor theses are clearly too high. Nevertheless, these two surveys show that at least concerns about one's own body odour are not uncommon, even though there may be no clinical picture. In halitosis consultations, prevalences of 12%–27% were found among those who fear that they are spreading an unpleasant halitosis (Nagel, Lutz & Fillippi, 2006; Quirynen, Dadamio, van den Velde, et al., 2009). Little is known about the gender ratio. Greenberg et al. (2016) reported in their study 66,8% male, 32,8% female participants and 0,4% participants of other gender (Greenberg et al., 2016). At Phillips and Menard (2011), more women (60%) than men (40%) participated (Phillips & Menard, 2011).

According to Greenberg et al. (2016), 54% of their study participants were affected by a chronic course (Greenberg et al., 2016), Phillips and Menard (2011) stated that people with the disorder had already suffered from the disorder for an average of 16,6 years ( $SD = 15,5$ ) before the study (Phillips & Menard, 2011). There is also little reliable information about the beginning of the disorder. The study by Greenberg et al. (2016) proclaimed that those affected typically indicated that the symptoms developed during early adulthood and found a mean age of onset of 21,1 years (Greenberg et al., 2016). In the Phillips and Menard study, ORD usually started during adolescence, with 2/3 of those affected stated an onset of the disease before age 18 (Phillips & Menard, 2011). The review by Begum and McKenna (2011) reports an average age of onset of 21 years, however, in 58% of the cases, the age of onset was before the age of 20 (Begum & McKenna, 2011).

## 2.2 Classification of the ORD

This is also a disorder that has been described for more than 100 years. For the first time, Pryse-Phillips (1971) investigated the phenomenon empirically and named it "Olfactory Reference Syndrome" (Pryse-Phillips, 1971). However, the ORD has not yet been included in the classification systems as a distinct disorder. Prior to the recent revision of the DSM, there was a thorough discussion about including the ORD as an independent disorder (still called "olfactory reference syndrome") in the DSM-5. The diagnostic criteria discussed at the time by the DSM-5 Task Force (Working Group "Anxiety, Obsessive-Compulsive Spectrum, Posttraumatic, and Dissociative Disorders") were: "A. Preoccupation with the belief that one emits a foul or offensive body odor although this odor is not perceived by others, B. At some point during the course of the disorder, the person has performed repetitive behaviors (e.g., washing body, changing clothes) or mental acts (e.g. comparing their body odor with

that of others) in response to the odor concerns, C. The preoccupation causes clinically significant distress (for example, depressed mood, anxiety, shame) or impairment in social, occupational, or other important areas of functioning, D. The preoccupations are not due to a general medical condition, E. The preoccupations are not restricted to the symptoms of another mental disorder (e.g., the delusions of Schizophrenia or another Psychotic Disorder)" (APA, 2011). However, it was ultimately decided not to include ORD in DSM-5, but it is mentioned among the "Other Specified Obsessive-Compulsive and Related Disorders" (APA, 2013). There it is referred to as a synonym for a culture-bound disorder called "Jikoshu-kyofu", a disorder in which those affected are convinced that they are spreading an unpleasant body odour (APA, 2013). Culture-bound because "Jikoshu-kyofu" is a subcategory of the Japanese "Taijin Kyofusho", a disorder that combines aspects of various western disorders (social anxiety disorder, BDD and ORD) (APA, 2013; Schmidt et al., 2017; Suzuki, Takei, Kawai, Minabe, & Mori, 2003) into a whole.

According to ICD-10, it is so far only possible to classify a delusional appearance of ORD, namely (analogous to the delusional form of BDD) as other persistent delusional disorder (F22.8; WHO, 1992). Following the adoption of the ICD-11 in May 2019, it is now certain that the ORD will be included in the ICD-11, subsumed under obsessive-compulsive or related disorders (WHO, 2019), where the term "Olfactory Reference Disorder" is now officially introduced. The changed terminology (from "syndrome" to "disorder") accentuates the assumption that ORD is not just a syndrome of another, already known disorder (Veale & Matsunaga, 2014). The following description of ORD is given for ICD-11: "Olfactory Reference Disorder is characterized by persistent preoccupation with the belief that one is emitting a perceived foul or offensive body odour or breath that is either unnoticeable or only slightly noticeable to others. Individuals experience excessive self-consciousness about the perceived odour, often with ideas of reference (i.e., the conviction that people are taking notice, judging, or talking about the odour). In response to their preoccupation, individuals engage in repetitive and excessive behaviours such as repeatedly checking for body odour or checking the perceived source of the smell, or repeatedly seeking reassurance, excessive attempts to camouflage, alter, or prevent the perceived odour, or marked avoidance of social situations or triggers that increase distress about the perceived foul or offensive odour. The symptoms are sufficiently severe to result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning" (WHO, 2019). Furthermore, it can then be specified whether the insight is adequate to good, or bad to missing (WHO, 2019).

### 2.3 Differential diagnosis and comorbidities of ORD

Due to the current lack of studies on ORD, there are currently no empirically proven suggestions on how to distinguish ORD from other disorders. However, based on the phenomenological descriptions of the disorder, deductions can still be made (Schmidt, 2019). A differential diagnostic differentiation of ORD from psychotic/ delusional disorders, BDD, obsessive-compulsive, social anxiety, and hypochondriac disorders is recommended (Schmidt, 2019). With the psychotic/delusional disorders, links are the fixed (delusional) beliefs, referential thinking and possibly hallucination. Here one has to consider the contents of the beliefs and hallucinations: according to the review by Begum and McKenna (2011), in the case of ORD, the contents of delusional beliefs as well as ideas of references and hallucinations refer exclusively to the smell; no person from the case vignettes referred to news from the newspaper or television, which is often the case with original psychotic disorder (Begum & McKenna, 2011). In the context of schizophrenia (in contrast to ORD), odours are more likely to be described that can be in the person's surroundings and have no relation to their own body (Pryse-Phillips, 1971; Schmidt, 2019). As a result, there are usually no compensatory safety behaviours in schizophrenia if the odour cannot be assigned to one's own body (Pryse-Phillips, 1971, Schmidt, 2019). Lochner and Stein (2003) assume that insight is in a continuum in ORD and that hallucinations can also be experienced in times of delusional manifestations (Lochner & Stein, 2003). That ORD and BDD seem to have a lot in common is shown, among other things, by the fact that both disorders are similarly conceptualised in the ICD-11; the only differentiating criterion is the type of flaw (appearance versus smell; WHO, 2019). This is also the most important differential diagnostic consideration: what are the contents of the beliefs and why is a certain safety behaviour carried out – should the appearance be influenced or the body odour? Intrusive thoughts and repetitive behaviours are the link to the obsessive-compulsive disorders, here the focus should be on the content of the intrusive thoughts: should certain rituals influence one's own smell, or should contamination be prevented, e.g. as part of compulsory washing (Schmidt, 2019)? In addition, those affected by compulsion (often in contrast to those affected by ORD) usually have the insight that at least one coercive thought/ action is exaggerated or nonsensical (WHO, 1991). ORD connects the fear of and avoidance of social situations due to the fear of negative evaluation and rejection with the social anxiety disorder – the differentiating question is whether evaluation fears exist due to the smell versus due to the behaviour (Schmidt, 2019). However, people with social anxiety disorder are often afraid of be-

ing noticed through heavy sweating, while ORD sufferers often suffer from the fear of smelling like sweat (Lochner & Stein, 2003). Nevertheless, the social anxiety disorder seems to be more about the visibility of sweat (e.g. spots under the armpits) (Feusner, Phillips, & Stein, 2010), and ORD is more about the smell of sweat itself (Schmidt, 2019). In the case of social anxiety disorder, there are also no regular repetitive behaviours (Tada & Kojima, 2002). A common feature of hypochondria and ORD is that in both disorders sufferers often scan their bodies for symptoms and seek medical treatment, but negative medical findings can only improve their anxiety (if at all) in the short term (Schmidt, 2019; Schwind, Rohrman, Bechtoldt & Weck, 2014). For people with ORD, however, it is crucial that they do all of these things not because they are afraid of a serious physical illness, but because they suspect that there is a physical abnormality that could explain the odour and that this could possibly be corrected by medical diagnosis and treatment (Schmidt, 2019).

With regard to comorbidities, Greenberg et al. (2016) report that the participants reported significant anxiety and depressive symptoms; further symptoms were not explored within this study (Greenberg et al., 2016). In the study by Phillips and Menard (2011), 95% of those affected suffered from an mood affective disorder, mostly depression (85%), 15% from a psychotic disorder, 50% a substance-related disorder, 80% from an anxiety disorder ( here most prominent the social anxiety disorder with 65%), no person from a somatoform disorder and 5% from an eating disorder (Phillips & Menard , 2011). In their review, Begum and McKenna conclude that depressed mood was present in 39% of the cases included in the review, and anxiety in a broader sense in 42% (Begum & McKenna, 2011). In a Brazilian study of 14 patients, 71,4% had a comorbid depression and 50% had an obsessive-compulsive disorder (Prazeres, et al., 2010). Other frequently reported comorbidities are social anxiety disorder (Lochner & Stein, 2003), substance abuse (Luckhaus, Jacob, Zielasek, & Sand, 2009) and BDD (Phillips et al., 2005)

## 2.4 Treatment of ORD

To date, there are no randomized controlled therapy studies on the treatment of ORD, but some casuistries have been published in which the patients received medication and/ or psychotherapy (sometimes in parallel). As with BDD people with ORD do not start psychiatric/ psychotherapeutic treatment until late, in the study by Prazeres et al. (2010) only 14 years after the onset of the disorder. This is also due to the fact that those affected initially prefer non-psychiatric/ psychotherapeutic treatments in the hope that medical treatment will eliminate the odour (Greenberg, Berman, Braddick, Schwartz,

Mothi, & Wilhelm, 2017). However, non-psychiatric/ psychotherapeutic treatments do not relieve symptoms and can also lead to exacerbation (Miranda- Sivelo, Bajo- Del Pozo, & Fructuoso-Castellar, 2013; Phillips & Menard, 2011). Greenberg et al. (2017) have explored high demand behaviour and treatment barriers among ORD sufferers, and also came to the conclusion that 44% of respondents visit specialists primarily, while only 14% seek psychiatric/ psychotherapeutic treatment (Greenberg et al., 2017). The authors defined treatment barriers as 1. logistical and financial barriers (e.g., "I was worried about what it would cost"), 2. barriers due to stigma, shame and discrimination (e.g. "I was ashamed of my problems") and 3. barriers related to attitudes and satisfaction with treatment (e.g. "I didn't think treatment could help") (Greenberg et al., 2017). Of those surveyed, 92,1% cited logistical and financial barriers, 91,3% barriers due to stigma, shame and discrimination, and 79,8% barriers related to attitudes and satisfaction with treatments (Greenberg et al., 2016). Especially an increased shame (reported by 55,7% of the participants) seems to make it more difficult to establish contact (Greenberg et al., 2017). Unfortunately, there are still no studies as to whether difficulties can also be expected with ORD in the initial consultation or in the first phase of therapy. But if you focus on the treatment barriers and take into account the affinity of those affected to seek primarily non-psychiatric/ psychotherapeutic treatment, it is probably more likely that this group of patients also requires a special motivation build-up.

In their review Begum & McKenna (2011) were able to determine result data for 76 casuistries, with follow-up periods between two weeks and 10 years (on average 21 months) (Begum & McKenna, 2011). Of the cases, 30% were described as remitted, 37% as improved and 33% as not improved or worsened (Begum & McKenna, 2015). The review reports that 78% of the patients benefited from psychotherapy, including various therapeutic modalities, but mainly cognitive behavioural therapy (Begum & McKenna, 2011). However, there is not yet enough research to be able to make reliable statements about which form of therapy is suitable (individual versus group therapy), which therapy school or how long psychotherapy should last (Thomas, du Plessis, Chiliza, Lochner, & Stein, 2015). There are also no treatment manuals.

In addition to psychotherapy, various individual case studies have also investigated whether and, if so, which psychopharmacological treatments can lead to an improvement in symptoms, also summarised in two reviews (Begum & McKenna, 2011; Thomas et al., 2015). Antidepressants or neuroleptics were used most frequently, sometimes in combination (Begum & McKenna, 2011; Thomas et al., 2015). In the case of antidepressants, there are reports of the use of tricyclics, fluoxetine, paroxetine, citalopram and sertraline – but the results are



contradictory, the studies are difficult to compare, and in addition, there has often been a combination with other psychotropic medication and/or psychotherapy, which makes it difficult to assess their effectiveness (Begum & McKenna; Thomas et al., 2015). A similar picture emerges for neuroleptics: Begum and McKenna (2011) found that 33% of the patients showed improvement after taking neuroleptics alone, compared to 55% improvement after taking antidepressants alone (Begum & McKenna, 2011). Overall, neuroleptics seem to be less promising than antidepressants, with a success rate between 10%–50% (Phillips & Castle, 2007; Schmidt, 2019). But also, with regard to the administration of psychotropic medication, the study situation is still too thin to be able to make reliable statements (Thomas et al., 2015).

### 3 Similarities and differences between BDD and ORD

Similarities and differences between the two disorders are mainly derived from clinical observations, and were particularly discussed during the revisions of DSM and ICD (e.g. Feusner et al., 2010; Veale & Matsunaga, 2014). The fact that there are phe-

nomenologically large overlaps between the two disorders is also shown by the new conceptualization in the ICD-11, where both disorders only differ in the type of blemish perceived (appearance versus smell) (WHO, 2019). Empirical studies directly comparing the two disorders have so far only one cross-sectional study focusing on the comparison of social anxieties, delusional symptoms, body-related emotions and interpersonal problems in  $n=21$  persons each with BDD, ORD and a psychologically healthy control group (Schmidt & Grocholewski, 2018). In this study, group differences were found with regard to socio-phobic and delusional symptoms, body-related emotions and interpersonal problems (Schmidt & Grocholewski, 2018). There were no significant differences in social anxiety between the two clinical groups (but significant differences to the control group); the BDD group differed significantly from the control group in terms of delusional symptoms, but not from the ORD group, which was not significantly different from the control group (Schmidt & Grocholewski, 2018). In terms of body-related emotions, the BDD group showed significantly lower values than the other two groups for “interest” and “joy” towards their body, and instead significantly higher values for “sadness”, “anger”, “disgust”, “contempt”, “fear” and

**Table 1**

Cross-disorder and disorder-specific proportions of body dysmorphic disorder and olfactory reference disorder

Disorder-specific BDD	Cross-disorder proportions	Disorder-specific ORD
Worries about being ugly or disfigured	Fear of and/or avoidance of social situations, fear of evaluation and rejection by others Flaw cannot be objectified from the outside Delusional beliefs are often	Concern to spread an unpleasant smell
Only related to aspects relevant to appearance (e.g. someone speaks disparagingly about appearance)	Ideas of reference	Only related to odour-relevant aspects (e.g. someone opens the window because of the alleged bad smell) Olfactory hallucinations are described more frequently
Because of the appearance	Feelings of shame	Due to the alleged inherent odour
Manipulation/concealment of appearance e.g. mirror/ reflecting surfaces	Repetitive thinking and safety behaviour Avoidance behaviour (social situations and triggers for increased stress due to fears) High rate of suicidal thoughts/attempts Severe social and professional restrictions	Manipulation/ masking the smell
Point prevalence in the general population about 2%.	Chronic course	Prevalence unknown
Onset of disorder in adolescence		No definite findings regarding the onset of the disorder, presumably in early adulthood
Comorbidity with eating disorders and cluster C personality disorders	Comorbidity with depression, social anxiety disorder, obsessive-compulsive disorder, substance abuse/dependence	Comorbidity with BDD
To correct the appearance, e.g. medical cosmetic treatments	High use of non-psychiatric/ psychotherapeutic measures	For clarifying medical findings that could explain the odour and, if necessary, eliminate it
Cognitive behavioural therapy particularly well documented	Effectiveness of psychotherapy	So far only proven in individual case studies; no reliable statements about the type/form of therapy possible
Effectiveness of SSRIs particularly well documented; dosage instructions exist	Effectiveness of antidepressants	So far only proven in individual case studies; no reliable statements possible

Note: BDD= Body dysmorphic disorder, ORD= Olfactory reference disorder

"shame"; the ORD group and the control group did not differ in their body-related emotions (Schmidt & Grocholewski, 2018). In comparison to the BDD group, ORD patients reported positive body-related emotions more often (Schmidt & Grocholewski, 2018). No significant differences were found between the ORD and control group with regard to interactional problems, but the BDD group differed significantly from the comparison group with regard to a dismissive-cold and introverted-avoiding interaction style (Schmidt & Grocholewski, 2018).

Table 1 summarizes the similarities (cross-disorder proportions) and differences (disorder-specific proportions) of BDD and ORD.

#### 4 Summary and outlook

We are dealing with two mental disorders in both BDD and ORD, which are underrepresented in both clinical practice and research compared to other disorders. For ORD in particular, it is currently hardly possible to derive empirically proven findings.

For BDD, the research situation has fortunately become more denser over the last two decades, and in Germany, too, various research groups are now working on BDD. In 2016, the scientific network body dysmorphic disorder (KDS-Net) was launched; seven female researchers from Germany are represented in this network. With the inclusion of renowned German and European researchers as guests, the KDS-Net is intended to lead to stronger German and European networking in the research field. In addition, existing supply structures are to be standardized, strengthened and improved and the German public is to be made aware of the disorder which is not yet sufficiently known. A first step has already been taken to raise awareness of this disorder among patients, relatives and those providing treatment; since October 2018 there has been a website providing information at <http://www.kds-net.com/>. The underrepresentation of BDD in clinical practice can be explained by various factors. On the one hand, apparently treating people are not yet sufficiently familiar with this disorder; on the other hand, questions on BDD were not yet included in the DSM-IV versions of the structured diagnostic interviews (in the DSM-5 versions, they are), so there were no routine queries; this means that the BDD is often not adequately recognized or misdiagnosed (Buhlmann, 2011; Hartmann et al., 2019). In addition, those affected do not primarily enter the psychiatric/ psychotherapeutic setting with their complaints, but first seek treatment measures that directly address the blemish (e.g. Crerand et al., 2005). Shame is also the most common reason why those affected do not seek adequate professional treatment, followed by a belief that nobody could understand the appearance-related problems or that they are not yet ready

for psychotherapy (Buhlmann, 2011). There is still a lot of investment to be made to lower the treatment barriers so that more of those affected can engage in psychotherapy (Buhlmann, 2011). A promising first step could be internet-based therapies, for example. In Sweden, a 12 weeks therapy-guided, internet-based CBT was conducted as a single blind, randomised controlled trial, with the result, that this form of intervention was well accepted by those affected and led to a significant reduction in the symptoms of BDD (Enander et al., 2016). The research group proclaimed the usefulness of the Internet therapy in an approach of stepped care for people affected with mild to moderate symptoms and a low risk of suicide (Enander et al., 2016). In a two-year follow-up study, the effects achieved by internet therapy were found to be stable by consensus (Enander et al., 2019).

With regard to the ORD, research is literally still in its infancy. The research landscape mainly consists of qualitative individual case studies; published empirical studies in which more than 25 ORD sufferers (versus individual ORD symptoms) were investigated are very manageable, e.g. the first systematic study ever with  $N = 36$  (Pryse-Phillips, 1971), a Japanese study with  $N = 38$  (Yamada, Shigemoto, Kashiwamura, Nakamura, & Ota, 1977), a Nigerian study with  $N = 32$  (Iwu & Akpata, 1990), a German study with  $N = 30$  (Schmidt & Grocholewski, 2019) and the large-scale online study with  $N = 253$  participants from Greenberg et al. from 2010. This has already produced three valuable publications that have provided information on clinical features, treatment barriers, and ego-centric and allocentric anxieties based on this large sample (Greenberg et al., 2016; Greenberg et al., 2017; Greenberg, Weingarden, & Wilhelm, 2018). We also find a blatant lack of basic studies (which, for example, deal with the mechanisms of the disorder) or (quasi-) experimental investigations: there is not a single publication on this subject so far. The only basic study worldwide (to our knowledge) is currently taking place in Germany, although publications are still pending. As with BDD, the underrepresentation in clinical practice can be explained here in particular by ignorance about the disorder (Schmidt et al., 2017); to date, neither ORD symptoms have been assessed through structured diagnostic interviews, nor do validated self-reporting measures exist for the German-speaking area. Analogous to BDD, we find patients primarily in other treatment contexts because they hope to be able to get rid of the odour through targeted medical measures (Greenberg et al., 2017). Together with the treatment barriers described in the empirical studies, especially shame (Greenberg et al., 2017), this means that we can hardly make out those affected in the psychiatric/ psychotherapeutic setting. For psychotherapy with ORD sufferers, there are hardly any reliable findings that helps to adapt therapeutic action to the needs of ORD sufferers,

therapists are encouraged to adapt their knowledge flexibly and to deal sensitively with shameful topics (Schmidt et al., 2017).

Conclusion: For both BDD and ORD, it is important to both intensify research and to bring the two disorders more deeply into the awareness of those treating them so that they are not "overlooked" in the clinical treatment context. Both disorders are severely socially and professionally impairing disorders with a chronic course and a high rate of suicidal thoughts and actions, which can have negative implications if overlooked. In addition, treatment barriers need to be further lowered, so that those affected can seek low-threshold psychiatric/ psychotherapeutic help if necessary.

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