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Inventory for the Assessment of the Severity of Body Integrity Dysphoria (the BID Assessment)

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Abstract

Objective:*Body integrity dysphoria (BID; also known as body integrity identity disorder, xenomelia, amputee identity disorder, or apotemnophilia) describes a very rare condition in which non-disabled people feel a desire or need for a physical disability (e.g., amputation, paralysis, or blindness). BID is included in the new version of ICD-11 (6C21: body integrity dysphoria), but, thus far, we are without a standard test of whether a subject suffers from BID and, if so, at what intensity. Accordingly, this study aimed to develop an inventory for the assessment of BID.* Methods*: We created a questionnaire comprising 80 items covering the desire for amputation alongside possible incongruities between an individual's mental image of themselves and their actual physical condition and appearance. The questionnaire assesses six dimensions of the respondent's experience: 1. Influence of BID on day-to-day life, work, and dreams (12 items); 2. Perceived need for a disabled body (13 items); 3. Influence of BID on relationships and sexuality (7 items); 4. Influence of BID on emotions (10 items); 5. Development of BID in childhood and adolescence (4 items); 6. Coming out, interaction with others, official certification (6 items).* Results*: We collected data from 213 BID sufferers (a comprehensive sample size, considering the rarity of the disorder). The findings show a significant difference ($p < .05$) in subjectively perceived psychological distress between those expressing a desire for amputation, palsy, or other desires. We further identified significant coherence between the severity of the disorder and the age of manifestation, number of therapeutic options attempted, and presence of an erotic component. The findings enabled us to develop a classification of severity for BID that will prove valuable to the diagnosis of the disorder and selection of therapeutic options.*

Introduction

A very small group of people with intact bodies feel the need to have a disability such as amputation, paralysis, blindness, toothlessness, incontinence, or another condition (First, 2005). They may refer to themselves as *wannabes* (Kasten, 2012). Indeed, they may attempt to achieve the desired disability; First (2005) and First and Fisher (2012) have found that many BID sufferers have undergone surgery to adjust appearance of their real body to a mental image.

Initially, the symptoms as described below were termed apotemnophilia, xenomelia, amputee identity disorder, or body integrity identity disorder (BIID). The disorder's inclusion in the World Health Organization (2019) *International Statistical Classification of Diseases and Related Health Problems* (11th ed.; *ICD-11*) and the American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5)* has seen a renaming to *body integrity disorder* (BID). The condition usually develops in childhood or early adolescence and often represents a perceived need that extends across the patient's entire lifespan (First, 2005). The predominant focus of this desire for disability is the removal of limbs (First, 2005). However, it may also involve wishing for a loss of sensory capabilities, such as blindness, deafness, or paralysis (Kasten, 2009). The sufferer does not perceive the body part that focuses on the dysphoria as belonging to the rest of the body; some BID sufferers even describe a feeling of being "overcomplete" (First, 2005). The ensuing constant bodily focus from the condition may impact friendships, intimate relationships, and careers (First, 2005; Kasten, 2009).

The urge for a disability may be so intense that those affected try to achieve a visual approximation of their desired body image (e.g., binding an undesired part of the body, using crutches, or a wheelchair; First & Fisher, 2012). For those with other foci, this may mean plugging the ears with cotton wool (Veale, 2006) or wearing black lenses and using a cane (Kasten, 2012). People with BID call these behaviors *pretending* (Kasten, 2012). Dissatisfaction with the body can increase to the extent that they resort to radical methods, such as freezing limb tissue in dry ice, triggering infection, or amputating by placing the limb on railway tracks (Beresford, 1980; Parsons et al., 1981). Alternatively, those with BID may seek surgery, which may be illegal (Kasten, 2012). Unscrupulous individuals or organizations may exploit the desperation of sufferers (Barrow & Oyebode, 2019), as happened to a person in Scotland who paid $20,000 for an amputation that never took place (Mercer, 2017). Due to the shame surrounding the condition and the concomitant secrecy, a sufferer may make contrived excuses to others after surgery, ascribing their state to a car accident or serious infection (Noll & Kasten, 2014).

Since the turn of the millennium, BID has gained increased attention among researchers, especially when amputation is the focus (Dixon, 1983; Parsons et al., 1981). In 1997, Bruno reported the case of a woman who had no desire for amputation, but chronically used a wheelchair. Similarly, two of the 52 sufferers interviewed by First (2005) did not desire amputation, but rather paraplegia. The study carried out in 2014 by Noll and Kasten (2014) found that 23.8% of the successful BID sufferers did not feel the need for amputation of a body part, or at least not exclusively. Veale (2006) published the case of a woman who felt a strong desire for complete numbness; despite the presence of numerous BID symptoms, misophonia was initially suspected. Interestingly, individuals with a need for blindness showed exaggerated responses to visual stimuli and consequently perceived visual impairment as more relaxing (Gutschke et al., 2017). The desire for a toothless mouth also appears in the literature; Noll and Kasten (2014) described a man who had his teeth removed by a doctor at age 67.

Although numerous studies speak of a deep desire for various disabilities (Aner et al., 2018; First, 2005; Noll & Kasten, 2014), these conditions have received little attention. Aner and colleagues (2018) found those with or without BID gave differing attractiveness ratings to drawings depicting people with disabilities. Within the BID group, differences were seen depending on the desire for paralysis versus amputation. The authors took this to indicate that the types of disability differed in their perceived aesthetic value.

Until very recently, BID had yet to attain the status of an official diagnosis. However, the most recent edition of the *ICD-11* has included the condition:

> *Body integrity dysphoria* is characterized by an intense and persistent desire to become physically disabled in a significant way … with onset by early adolescence accompanied by persistent discomfort, or intense feelings of inappropriateness concerning current non-disabled body configuration. The desire to become physically disabled results in harmful consequences, as manifested by either the preoccupation with the desire … significantly interfering with productivity, with leisure activities, or with social functioning … or by attempts to actually become disabled. It results in the person putting his or her health or life in significant jeopardy.
> (https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/256572629)

This new diagnosis indicates a need for tests to investigate the presence and extent of BID. We currently remain without a test of the disorder's intensity and the influence of its specific manifestation on the general pattern.

It appeared evident to us that developing a questionnaire that could capture an affected individual's perceptions and intensity would facilitate correct diagnosis and individual treatment planning. Accordingly, the questionnaire discussed in what follows had the aim of establishing the relationship between the severity of BID and known factors of BID symptomatology, such as early onset (First, 2005), the erotic component frequently present (Dixon, 1983), and the lack of effectiveness of existing therapies (Kröger et al., 2014). It includes questions of high specificity, to the end of capturing the construct and variety of BID more effectively than extant questionnaires with an exclusive focus on the desire for amputation (Fischer, 2015).

Method

The authors developed an 80-item questionnaire based partly on the BIID Questionnaire (Spithaler & Kasten, 2009) and the Body Integrity Identity Disorder – Screening of Grade and Intensity (Fisher et al., 2015); we modified and revised most questions taken from these two inventories, and added several original items. Our principal objective was to acquire information about desired bodily changes, including amputation. The questionnaire encompasses both open-text fields and a total of 52 multiple-choice questions using a five-level Likert scale (1 = *disagree strongly*; *2 = disagree*; 3 = *it depends*; 4 = *agree*; 5 = *agree strongly*). The 28 open-text questions relate to demographic data, the respondent's current physical condition, previous illnesses and operations, and their desired physical condition.

The questionnaire asks respondents to describe, in the last six months, the impact of the dysphoria, including:

1. Influence of BID on day-to-day life, work, and dreams (12 items),
2. Perceived need for a disabled body (13 items),
3. Influence of BID on relationships and sexuality (7 items),
4. Influence of BID on emotions (10 items),
5. Development of BID in childhood and adolescence (4 items),
6. Coming out, interaction with others, and official certification (6 items).

Further questions seek to ascertain the number of attempts the respondent had undertaken to adjust their physical body to mental image, beliefs on whether a successful physical adjustment would bring changes to their work lives, and whether they had attempted any form of psychotherapy, drug, or other treatment. The questionnaire also asks respondents to detail the frequency of BID-related thoughts, rumination, and ideas on how to change their body within a typical week, if they

have confided in others about their desire, and whether they would use a cover story if they underwent surgery. Finally, the questionnaire asks respondents to list advantages (pros) and disadvantages (cons) of their desired physical state. The findings from these open questions were not included in the statistical analysis.

Participants

We collected data from 213 individuals either diagnosed with BID, or who suspected themselves of having the condition. The inclusion criterion was knowledge of German or English. In addition, most of the participants were personally known to the study supervisor (Erich Kasten) or were members of BID-related self-help groups. We therefore consider the likelihood of respondents without BID having taken part in the study to be very low. Table 1 shows respondent demographic data.

Table 1

Demographic Data of Respondents

Male / female / other	162 / 43 / 8
Age (years)	42.11 (±14.71)
Sexual orientation:	
Heterosexual	126 (59%)
Homosexual	51 (24%)
Bisexual	31 (14%)
Pansexual	6 (3%)
Years of education	15.4
Marital status:	
Single	125 (59%)
Married	69 (32%)
Divorced	17 (8%)
Widowed	2 (1%)

As Table 2 illustrates, participants cited various types of desired disabilities. The total does not add up to 213 since some subjects expressed desires for two or more disabilities.

Table 2.

Distribution of Participants According to the Type of Disability Desired

Type of disability desired	Sample size
Amputation	141
Paralysis	64
Blindness	6
Incontinence	5
Deafness	2
Toothlessness	2
Other (e.g., stuttering, penectomy, mutism)	14

Results

Previous Psychiatric Diagnoses

Fifty-three (24.9%) of the participants stated that they had previously been diagnosed with a mental illness. None reported a diagnosis of a psychotic disorder such as schizophrenia. Depression was the type of condition most frequently mentioned (64%), followed by anxiety disorder (20%). It is worth noting that seven (3.2%) reported having Asperger's syndrome.

Severe Preexisting Physical/Chronic Conditions/Surgery

When asked about serious existing physical problems, participants primarily mentioned conditions prevalent in the general population, such as asthma, diabetes, cardiovascular diseases, hypertension, and migraines. None of these conditions occurred with remarkably high frequency. Only eight participants (3.8%) reported diseases or limb surgeries that involved their undesired body parts. However, all of these injuries occurred in adulthood, and after the initial appearance of BID symptomatology, which would appear to refute the hypothesis of BID as stemming from the repression of the trauma of a painful body part in childhood (Kasten, 2012).

Neurological Conditions

One respondent (0.4%) reported a severe skull fracture as a result of an accident; the injury, however, was sustained in the respondent's fiftieth year of age, while BID symptomatology had manifested much earlier, at the age of eleven. In a contrasting finding, two participants (0.9%) who

had been treated for meningitis at two weeks and ten years of age respectively both reported onset of BID disease at ages six and twelve. These findings, alongside the similar observations made in previous studies, suggest a cerebral element to the disease's cause (Müller, 2007).

Focal Body Part

The data on the respondents' undesired body parts revealed a marked focus on the lower extremities. Just 13 participants (6.1%) wished to lose or paralyze their arm, and five, their hands (usually in addition to amputation of a leg, or indecision over leg or arm). In the case of a desire for paraplegia, paralysis was largely wished below the waist. The most expressed need was amputation of a leg above the knee. These observations are consistent with numerous existing studies, such as those by First (2005), Blanke et al. (2009), and Noll and Kasten (2014).

Variations in Desire over the Lifetime

Sixty-two percent of participants did not recall changes to their perceived need over their lifetime. Of those who reported a change, 21% said that the need increased. Many respondents lived with their condition long-term, becoming accustomed to the associated feelings. One interviewee stated that he gained more time to cope with his condition once he had retired. Another interviewee mentioned the internet as an intensifier of the symptoms.

In about 10% of respondents, the intensity of perceived need varied over time. Some described this as dependent on the amount of time they could successfully distract themselves from the symptoms. In contrast, four participants indicated that their dysphoria declined with age, reporting the apex of their yearning occurring in their youth, during which they undertook attempts to self-amputate, or, in one case, experienced the desire to lose all four limbs. One individual explained the decreasing intensity of his desire for surgery by increasing his pretending behavior, which showed him the limitations and disadvantages of a physical disability. Interestingly, respondents essentially gave practical, rational explanations (e.g., the ability to drive) for their preference for limbs on the right or left side of the body.

Four participants (1.8%) explicitly stated that the perception of a person with a disability increased their feeling of need or made their desire more specific. In this context, we note the findings of studies by Obernolte and colleagues (2015) that the childhood of people affected by BID featured several relatives, friends, neighbors, or others with disabilities that were at higher frequencies than would be expected. One participant gave a highly vivid account of the trajectory from vague interest, to the sensing of an exact desired amputation site, and the specific idea of the envisaged stump's appearance:

> I remember just trying it once and it hit me like [a] bolt of lightning ... . I suddenly felt: This is me. This is my identity. This moment was undoubtedly determining in my specific desire to amputate. The more the possibility existed to reenact the desired amputation unobserved, the more specific [my] perception of the imaginary leg stump became. Over many years, this illusion developed from a left thigh that initially simply ended somewhere, to a right thigh stump that was precisely defined with scars and complex shaping. Approximately 40 years ago this stump took on its final form, anchored in my soul.

We rarely (1.8%) saw a change of focus from amputation to paralysis or vice versa. Where this occurred, the variation sometimes took place several times over the participant's lifespan. Again, such variances in preference appeared to stem predominantly from rational considerations, involving, for instance, a weighing up of the risks involved in the amputation of both legs versus

those of muscular atrophy from permanent use of a wheelchair. One respondent reported his preference was influenced by a television documentary; another suffered a disease that led to severe pain that made a complete amputation a more attractive prospect. Periods of depression and critical life situations also figured in our findings as triggers for increased desire.

Current Physical Condition

Approximately 50% of respondents reported being physically intact and unrestricted. However, 32% spent their daily lives continuously or mainly in a wheelchair, and 18% used prostheses, orthoses, or crutches. In addition, two subjects (0.9%) reported using a urinary catheter or incontinence products.

Prospective Changes in Work Capability

Approximately 49% of the respondents believed they would continue in their current employment without any adjustments after undergoing surgery to adjust their bodies to their mental self-image. However, those unsure whether a change of occupation would be necessary amounted to 23%, while 28% indicated that they would be unable to work, or a change of occupation would be inevitable.

Therapeutic Options Used

59% of respondents said they had never accessed any type of therapy. Among these were individuals who intensely disliked the idea of any treatment, other than one bringing about the realization of their desire, and considered therapy as ineffective. One of the participants, a medical doctor, wrote that in his experience, most therapists do not take BID seriously. Psychotherapy had previously been or was currently being undertaken by 19% of respondents, and relaxation techniques by 7%; 6% had taken or were currently taking psychopharmacological medication, mainly antidepressants. Most of the respondents identified pretending as their primary self-treatment method.

Time Invested in the Condition

Only 17% of the respondents stated that they did not perform any pretending behaviors. The remaining participants (83%) spent an average of 19.8 hours per week pretending; this relatively high figure stems from the fact that several participants used a wheelchair all the time. Most respondents said that they thought about BID almost all day, with the effect that, during each action they undertook, a mental "film" ran in the background, depicting images of how it would be to perform this action in the person's desired physical state. All in all, thinking about this desired state occupied an average of 60.8 hours per week, while thinking about a specific medical intervention took 34.5 hours. On average, the BID sufferers surveyed spent 31.6 hours a week thinking about causing themselves an injury or deliberately inducing a medical intervention via, for instance, infection.

Coming Out and Cover Stories

Ninety-two participants (43.2%) said that if they were to undergo successful realignment of their body to their desired state, they would use a *cover story* for their condition rather than telling the truth to others in their lives. The most frequently mentioned lie was an accident, followed by an infection, then a consequence of a disease from which they genuinely suffered. Fifty-three people (24.9%) were unsure how they would handle this. A third (31.9%) of the

respondents said they would tell those around them the truth. These figures contrast with the finding by Noll and Kasten (2014) that 76.2% of BID sufferers who had successfully achieved their desired status had told their families the true reason for their operation.

Advantages and Disadvantages of Disability

In a finding concordant with previous work (Kasten, 2009), this study suggests that BID sufferers are well aware of the consequences of fulfilling their desire. One participant cited long-term health risks, reduced life expectancy, partial loss of independence, limitations in beloved hobbies, and time with his children as the disadvantages of his desired physical condition. However, he weighed these against the prospect of relief from BID-related rumination currently occupying a large part of his daily life, associated concentration difficulties, and other issues. Further benefits mentioned by other participants ranged from access to parking spaces for people with disabilities to an anticipated greater sense of body positivity. As described by a majority of participants, the principal benefit appears to be the opportunity to live as one with their desired identity.

The 13.1% of participants who already underwent adaptive surgery confirmed these hopes. For example, a "successful" BID participant wrote:

> [My] thoughts are freer, because I don't have to think about BID and how to achieve it repeatedly. It gives me a lot more energy. At the age of 40 (after amputation) I realized for the first time in my life what it is like to live freely.

Data Preprocessing for Severity Calculation

We excluded seven (3.2%) of the group of 28 (13.1%) successful wannabes from the calculations regarding BID severity because they reported having experienced no further BID-related needs after surgery. The histogram (see Figure 1) shows a normal distribution for questions 18 through 69, as measured on a five-point Likert scale.

Proceeding from the assumption of normal distribution, we obtained a classification of levels of severity as set out in Table 3 below, with severity determined by the mean test value and the standard deviation calculated in each case. Each statistic represents the average score of items 18 through 69 on a five-point scale, with the total sum divided by 52.

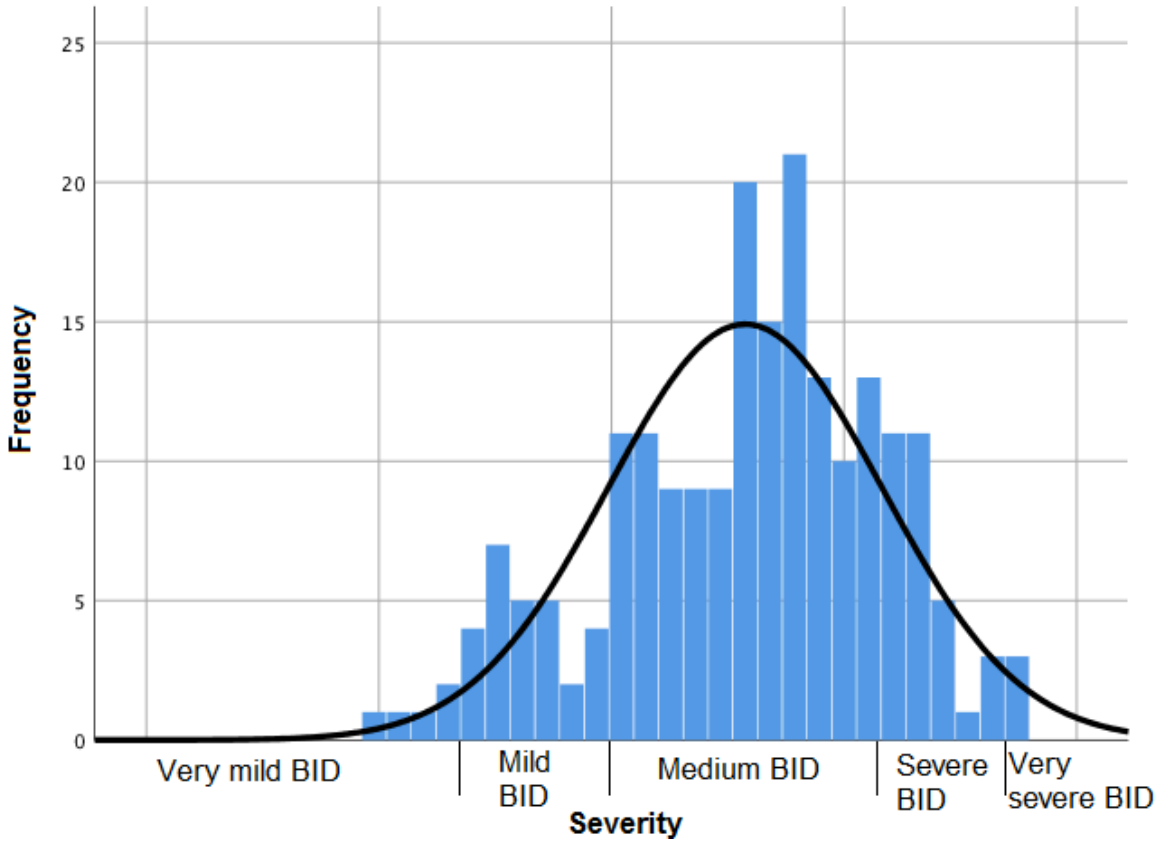
Table 3

Descriptive Statistics of the Severity of the Total Test

Very mild	Mild	Moderate	Severe	Very severe
< 2.39	2.39 – 2.97	2.98 – 4.16	4.17 – 4.75	> 4.75

Figure 1

Histogram of the normal distribution of severity of BID *on a 5-point scale (data relates to questions 18 – 69).*



Test Quality Criteria

The survey took place under equal conditions for all participants, online and without the influence of an interviewer, to assure objectivity. The questionnaire reliability attained an excellent value, with a Cronbach's α = .92. We ascertained internal consistency by calculating reliability coefficients of pairs of nearly identical items as follows: Items 21 and 28, Cronbach's α = .88; items 24 and 42, α = .80; items 51 and 54, α = .73. Checking whether a respondent gave similar answers for these pairs of items represents a good gauge of whether they took the questionnaire seriously and engaged with the items. We additionally formulated items 23, 39, 49, 54, and 65 in the opposite direction from the others, that is, in such a way that someone with no or very mild dysphoria might give an affirmative response (during the evaluation of the questionnaire, we reversed the values for these questions accordingly). This also serves as a test of consistency of responses; that is, if a person has high scores in most items, they will be expected to have low values on these questions.

We believe we have attained questionnaire content validity due to focus on the characteristic behaviors with which BID is associated, primarily the robust and persistent sense of a need for a physical disability, typical pretending behaviors, and the desire for an operation to adjust the body to the desired image. However, it will be a matter for future studies to test more

precisely whether BID-related questionnaires sufficiently capture the actual construct behind the disorder by comparing this test with, for example, the Zurich Xenomelia Scale (Aoyama et al., 2012).

Hypothesis Testing

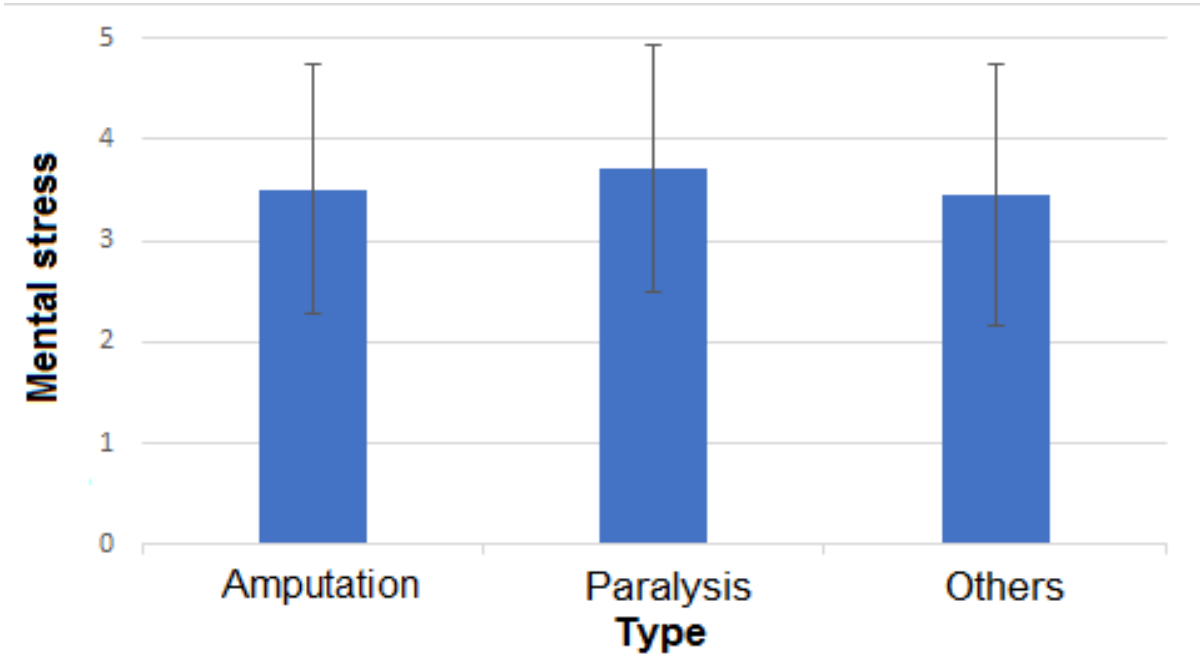
We created the variable *severity*, which results from all factors, for the following calculations:

- Hypothesis 1: The earlier the onset of the condition in childhood/adolescence, as recalled by the BID sufferer, the more severe the BID symptomatology. Recalled onset of BID symptomatology correlated significantly and negatively with disease severity (Pearson's $r = -.188$, $p = .003$).
- Hypothesis 2: The greater the severity of BID, the higher the number of treatment options used. The severity of the disease and the number of treatment options used correlate significantly ($r = .218$, $p = .001$).
- Hypothesis 3: The greater the severity of the dysphoria, the stronger the expression of the erotic component of the BID. The erotic component of the symptomatology correlates significantly with the severity of the disease ($r = .302$, $p < .001$).
- Hypothesis 4: BID sufferers with a desire for amputation experience greater psychological distress than BID sufferers with a desire for paralysis and BID sufferers with a desire for other disabilities. Mental distress differs significantly among groups *desire for amputation*, *desire for paralysis*, and *other desires*; χ^2 (2) = 5.45, $p = .030$. (Due to the small number of people in the sample with expressed needs other than amputation or paralysis and the lack of normal distribution, we used nonparametric methods, specifically the Kruskal–Wallis test, to calculate the rank sum of three groups for Hypothesis 4.)

Figure 2 shows that participants with a desire for amputation scored an average of 3.5 out of 5 of the possible units of mental distress (*SD* = 1.2). Those with a desire for paralysis scored an average of 3.7 (*SD* = 1.2), and those with a different desire scored 3.4 (*SD* = 1.2).

Figure 2

Mean values and standard deviations for perceived psychological distress among the groups desire for amputation, desire for paralysis, and other desires. Perceived psychological distress is given on a scale of 1 (not true at all) to 5 (yes, completely true).



Post hoc pairwise comparison (Dunn/Bonferroni test) shows that only the groups *desire for paralysis* and *other desires* differ significantly from each other ($z = 2.61$, $p = .027$). The effect strength of Cohen's d is .28 and thus describes a weak effect. The severity of dysphoria ($p = .225$), erotic component ($p = .383$), frequency of variations ($p = .227$), recalled age of first manifestation ($p = .074$), and tendency to undertake professionally or self-administered action to adapt the body to the desired image ($p = .099$) do not differ significantly between the groups of BID-sufferers with a desire for amputation, paralysis, or other desires.

Conclusion

This study has uncovered differences in BID following the focal type of disability in each case and prompts a closer examination of these differences. These findings notwithstanding, we have observed that the actual construct of BID appears regardless of focal disability type. Our study cautions against a limitation of our conception of BID to a desire for amputation and paralysis and calls for further investigations, which might lead to a more precise delineation of the clinical picture. A further result of this study is a high-reliability measure of the characteristics of BID symptomatology. The replications of and correlations with the findings of numerous previous studies that have emerged show that the test captures the actual construct of BID, indicating suitability for diagnostic use.

Authors

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Appendix

BID Assessment (by M. A. Garbos & E. Kasten, 2020)

BID-Assessment (by M. Garbos & E. Kasten, 2020)

Name (or alias):	
1. Age:	years
2. Gender:	[ ] male [ ] female [ ] divers
3. Sexual orientation:	[ ] heterosexual [ ] homosexual [ ] bisexual [ ] pansexual
4. Years of education (including college and vocational training)	_____ years
5. Current profession	
6. Marital status:	[ ] unmarried [ ] married [ ] divorced [ ] widowed
7. Have you ever been diagnosed a mental disorder?	[ ] yes [ ] no If yes, what kind of diagnosis:
8. What kind of surgeries did you have? When did you undergo these surgeries?	
9. Did you ever been diagnosed any severe or chronical disease? (e.g. severe accidents, coronary, diabetes, kidney failure, migraine, hypertension, coronary heart diseases, neurodermatis, irritable colon etc.)	[ ] yes [ ] no If yes, what kind of diagnosis and when have you been diagnosed?
10. Did you ever been diagnosed any neurological diseases? (e.g. stroke, meningitis, aneurysm etc.)	[ ] yes [ ] no If yes, what kind of diagnosis and when have you been diagnosed?
11. At about what age did you first noticed an incongruity between your mental and your real body image (BID)?	
12. Which body part(s) is/are affected by the need for amputation/paralysis and how does the physical disability look like? (Please provide a short explanation)	
13. What is your current physical condition? (e.g.: confined to a wheel-chair, using orthesis etc.)	
14. What kind of incongruity between your mental and your real body image do you perceive?	[ ] amputation [ ] blindness [ ] paralysis [ ] deafness [ ] incontinence [toothlessness [ ] others (please define):
15. Did the need ever varied over lifetime? (Please provide a short explanation):	[ ] yes [ ] no If yes, what kind of variation and when did it happen (year)?
16. What were the reasons for the variation of the desire?	
17. Are you amputated? (Or have a palsy, blindness, toothlessness, inkontingency)	[ ] yes [ ] no If yes, what body part and when did it happen?

The following questions refer to the LAST 6 MONTHS:

	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	Score
18. Thinking about how I can achieve the physical change, occupies a lot of time.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
19. My everyday life suffers under the BID a lot.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
20. Rarely, I am able to distract myself from BID to the extent that I hardly notice it at that moment.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
21. In my dreams I see myself being disabled.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
22. I feel affected in my social life by the effects of BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
23.. I spend rare time thinking about BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
24. My thoughts about disability have a negative influence on my attention and concentration.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
25. I feel affected in my working life by the effects of BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
26. When I surf the web (or other media), I often watch out for websides showing disabled persons.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
27. I'm interested into sports for disabled persons, e.g. paralympics.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
28. While dreaming, I mainly see myself being disabled (in the desired bodily state).	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
29. Thinking about how I can achieve the desired bodily state, occupies a lot of time.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
30. I have the urge to pretend living the life of a disabled person (e.g crutsches or wheelchair)	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
31. To achieve the congruity between my real and my mental body image (BID), I would make use of drastical measures (e.g.: Using dry ice to suffer frostbite, infections, break your own bones, atrophy etc.)	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
32. I can't imagine continuing living without the desired disability.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
33. The body part, I don't sense being attached to my body, feels „inanimate".	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
34. I informed myself about phantom pain, bedsores (due to prostheses or sitting in the wheelchair) and other disadvantages of a disability.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
35. I plan on actually undergoing surgery (even would be willing to undergo illegal surgery abroad).	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
36. I'm putting aside money to adapt my real body image to my mental one (e.g.: by using wheelchairs, surgery, orthesis etc.)	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
37. I plan on actually undergoing surgery in the next two years or I am already confined to a wheelchair (or other disabilities).	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
38. I already tried to adjust my real to my mental body image (e.g.: Using dry ice to suffer frostbite, infections, break your own bones, atrophy etc.)	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
39.. I didn't prepare myself for undergoing BID related surgery or other methods (e.g. atrophy).	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
40. The desire for a BID related surgery is with me all the time.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	

41. I spend a lot of time thinking about which methods to use to adjust my real body state to my mental body image.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
42. I perceive my wish for the congruity between my mental and my real body image to be strong.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
43. I feel affected in my relationship by the incongruity between my mental and my real body image or I even avoid getting into relationships.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
44. I feel affected in my sex life by the incongruity between my mental and my real body image.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
45. I don't really care being a man or a woman.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
46. I feel sexual arousal when I am thinking about the desired disability.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
47. I feel sexual arousal while pretending to be disabled.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
48. Disabled persons (especially the ones, that have the disability I would like to have) are sexual attracting for me.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
49.. I think the imagination to achieve the desired disability is erotic.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
50. I often suffer from depression and loss of interest due to BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
51. I feel distress until undergoing surgery or BIID disappears in other way.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
52. At times, I notice the incongruity between my mental and my real body image a lot, it's nearly impossible for me to concentrate on other things.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
53. I consider my wish for amputation/paralysis to be unsufferable.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
54.. I don't suffer under the incongruity between my mental and my real body image.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
55. I feel tainted by BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
56. The BID related bodily changes (e.g. by undergoing surgery) would change my life for the better a lot.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
57. I have accepted the BID sickness as a part of my personality.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
58. I feel miserable with my current body state (not disabled).	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
59. When I am thinking about gaining the desired disability, I feel relieved, freed and happy.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
60. When I was a child or teeanager, disabled persons fascinated me.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
61. When I was a child or teenager, I drew disabled persons or cut and collected photographs with disabled persons.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
62. When I was sick as a child, my parents took care of me a lot more than usual.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
63. When I was a child or teenager, I watched films, in which disabled persons played a roll.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
64. It is important for me to be authorized as a disabled person (e.g. certificate of disability)	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	

65.. The people around me don't know about my BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
66. I want to show others, that I can manage the life of a disabled person.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
67. I had a „coming out", what means that I already told other people of my BID.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
68. When I would reach my desired disability, I already know what kind of excuse or medical reasons I would tell others.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
69. I don't like to show others the BID related body part, which is not part of my body ideal.	Strongly disagree	Rather disagree	It depends	Rather agree	Strongly agree	
T O T A L of items 18 – 69 (reverse results of items: 23, 39, 49, 54, 65)						

70. How often have you already attempted to do an amputation or a BIID related procedure yourself?	_____(Number of attempts)
71. Would there be any work-related changes, when your real body image would be adjusted to your mental one?	[ ] yes [ ] no [ ]maybe If yes, what would change:
72. What kind of therapie did you use to live with BID? (e.g.: drug treatment, psychotherapy, relaxation techniques)	

73. On average, how much time do you spend pretending being disabeled?	_____hours a week
74. On average, how much time do you spend thinking about the desired body image?	_____ hours a week
75. On average, how much time do you spend thinking about BID related surgery?	_____ hours a week
76. On average, how much time do you spend planning how you can cause the desired disability yourself in the future?	_____ hours a week
77. On average, how much time do you spend planning with which methods of self-mutilation you can enforce surgery?	_____ hours a week
78. Who did you tell about your desire? (e.g. partner, family, friends, colleagues, therapist, doctor etc.) Please provide a short explanation about how they reacted (i.e. positive, neutral, negative, or e.g. initially horrified, then understanding…)	
79. Would you tell others an excuse, if you could reach your desired body image?	[ ] Yes [ ] No [ ]Maybe If yes, what would you tell:

80. What are advantages and disadvantages of your desired bodily state? What would be better if you could reach this bodily state? What would be worse?

PRO

CONTRA

EVALUATION SHEET BID-TEST (Garbos & Kasten, 2020)

Check, whether answers of following items are similar:
items 21 + 28 [ ]
Items 24 + 42 [ ]
items 51 + 54 [ ]

Check, whether the following items are reverse to the other answers:
23 [ ]
39 [ ]
49 [ ]
54 [ ]
65 [ ]

Area	**Items**	**Score**	**Percent** (Points/number of items) x100
1. Influence of BID on everyday life, profession & dreams (12 items);	18 – 29 (min 12, max. 60 points; reverse item 23)		
2. Need for a disabled body (13 items);	30 – 42 (min 13, max 65 points, reverse item 39)		
3. Influence of BID on partnership and sexuality (7 items);	43 – 49 (min 7, max 35 points, reverse item 49)		
4. Influence of BID on emotions (10 items);	50 – 59 (min 10, max 50 points, reverse item 54)		
5. Development of BID in childhood and youth (4 items);	60 – 63 (min 4, max 20 points)		
6. Coming-out, interactions, official certification (6 items).	64 – 69 (min 6, max 30 points, reverse item 65)		
	Total Score:		
	Total Score / 52		

Interpretation of strength of BID:

Very mild	***Mild***	***Medium (3.57)***	***severe***	***Very severe***
< 2.39	*2.39 – 2.97*	*2.98 – 4.16*	*4.17 – 4.75*	*> 4.75*