Body Integrity Identity Disorder: Development and evaluation of an inventory for the assessment of the severity

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Abstract: Body Integrity Identity Disorder (BIID), the wish of subjects for an amputation of otherwise healthy limbs, is a rare disturbance. Until now, BIID was seen as a symptom affecting a group of people suffering from an urging desire for amputation. But while some of the BIID-affected people only have a weak wish for an amputation others show severe symptoms. The aim of this work was the development of a psychological test to measure the severity of the wish for amputation or palsy in BIID afflicted subjects. Additionally, we analyzed correlation with demographic data. We developed a survey in English and German language from which three pairs of similar items were created for a test of reliability. 45 people affected by BIID answered this survey (38 men, 7 women, age 42.6 ±12.4). After controlling for robustness, a normal distribution of the "BIID-severity" could be detected and the subjects were divided into 5 groups (<2 SD: very low, -2 to -1 SD: light, -1 to +1 SD: moderate, +1 to +2 SD: heavy, > +2 SD: very heavy BIID). The severity of BIID sufferers was not more pronounced in older than in younger subjects, but BIID affects more men than women and the first manifestation of BIID occurs predominantly in childhood.

Keywords: body integrity identity disorder, inventory, severity

1. Introduction

To the general public, Body Integrity Identity Disorder is a largely unknown disorder. Sufferers feel an intensive desire for a physical disability and it is the opinion of these people that only an amputation or palsy can bring their real body in line with the subjectively perceived "right" mental body scheme (First, 2005; Nohl & Kasten, 2013). Beginning in their childhood, sufferers have an intensive feeling that a healthy limb does not belong to their body. In most cases the target is a leg, but other limbs can be affected as well. Most commonly, the desire for amputation is below the left thigh, followed in frequency by a right and bilateral leg amputation (Johnson et al., 2011).

In some individuals the unwanted part of the body changes over time, often for purely pragmatic reasons, such as for example to continue driving (Kasten & Stirn, 2009).

The proportion of those who feel sexual arousal at the idea of being self-amputated is estimated to be 2/3, but in about 75% of these the sexual aspect has no priority (First, 2005; Kasten, 2009; Furth & Smith, 2000).

Almost all affected subjects show a kind of substitute behavior: *pretending* refers to faking the desired physical disability, e.g. the use of crutches or a wheelchair. The pretending behavior not only causes feelings of happiness and can bring relief, it is also useful to find out problems of the desired amputation or plegia in activities of daily living (Kasten, 2009).

The BIID afflicted people identify themselves as "Wannabe" (from "want to be"), other names for the strange urge are: “apotemnophilia”, “amputee identity disorder”, “Xenomelia” or "Body Incongruence Disorder" (see e.g.: Money & Jobaris, 1977; Bayne & Levi, 2005; Braam et al., 2006; McGeoch et al., 2011). Until now, no diagnostic cri-

teria exist for the classification of this disorder neither in the ICD-10 nor in the DSM-V. The onset is usually in childhood, often post-pubertal. Almost all BIID subjects report a key-event: When they have watched somebody with a handicap (e.g. a wheelchair user or peg-legged man), they felt a fascination for this kind of "otherness". This experience triggers the development to become an amputee. The desire has a persistent character, but is often associated with shame and guilt (Stirn et al., 2009).

So far, no psychotherapeutic or pharmacological therapy is known. Neither cognitive-behavioral nor psychodynamic therapy nor administration of antidepressants have shown satisfactory results, however, they can lead in some cases to a reduction of psychological stress from the desire (Braam et al., 2006; Thiel et al., 2009). Based on a study of 20 people who have successfully reached the desired amputation, it is supposed that a total disappearance of the suffering is possible only after an amputation of the limb (Noll & Kasten, 2014).

Until now, BIID was seen as symptom affecting people strongly as they suffer heavily from an urging desire for amputation. But from personal talks the authors learned that some of the BIID patients only have a weak wish for an amputation and were able to cope with this feeling without specific plans for an operation. The classification of the severity of BIID is an important question for future research. Therefore the main task of this work was the development of a psychological test to measure the strength of the wish for amputation or palsy in BIID afflicted subjects. Additionally this study investigated gender differences regarding the severity of BIID

2. Method

2.1. Participants and design

For recruiting participants, a link on a BIID webforum was published (www.biid-dach.org). The screening instrument aimed exclusively at BIID sufferers. Exclusion criteria were the presence of other diseases (e.g. schizophrenia, body dimorphic disorder). The questionnaire was not directed at sufferers who have already achieved their physical disability due to a surgical procedure. Because of an incomplete number of responses (> 20% missing items), the data of one subject were excluded from further analysis. BIID is an extremely rare disorder. Until now, the world's largest study included 52 subjects (First, 2005). In our study the data of 45 subjects were analyzed. For the norming procedure of a new test, this is a very small number. However, it was not possible to get a larger sample. The distribution of the demographic data of the sample is shown in **Table 1**.

Table 1. Demographic data

Criterion	Sample (n=45)
Male /female	38/7
Age (years)	42,6 (SD=12,38)
Sexual orientation	
Heterosexuell	37 (82,2%)
Homosexuell	8 (17,8%)
Bisexuell	0 (0%)
Marital status	
Single	22 (48,9%)
Divorced	17 (37,8%)
Married	5 (11,1%)
Widowed	1 (2,2%)
Education level in years	16,1

2.2. Instruments

The severity of BIID was investigated with a questionnaire, based on the existing literature. Demographic data (age, gender, sexual orientation, education level in years, current occupation, and marital status) are recorded at the beginning of the questionnaire (items 1-8). Then questions are asked (a) for the last six months and (b) the last 14 days to analyze both, habitual and current feelings and behaviors. The participants have the option of applying their statements on a 7-point Likert-scale from *strongly disagree* to *strongly agree*. For the investigation of the duration of individual BIID-thoughts and behaviors we used open answers. The screening questionnaire is currently available in a German and an English version.

3. Results

3.1. Statistical Analysis

For an analysis of this test's reliability three pairs of items with very similar content were asked in different parts of the questionnaire (Item 12/23, Item 15/25, Item 19/32). These pairs must have a high correlation to ensure that the

questionnaire was filled out reliably. Statistical analysis was made with SPSS. The open questions (item 9; Item 34-38) were transformed into categories to allow statistical analysis. The survey period for this study began in January 2013 and ended in April 2013.

The criterion of objectivity of this psychological test can be considered as given. Using an online-questionnaire, questions and answers are independent of the examiner and the situation; analysis and interpretation of the statements underlie a standardized instruction.

To increase the test-selectivity, all items with a correlation <.3 with the total-test-score were removed (items 17, 18, 21, 27, 28, 34 and 35). After elimination of these non-sharp items, Cronbach's Alpha rose from .866 to .929 and is therefore in the excellent range. The corrected discriminatory powers of the items were between .338 and .760.

Hereafter, the items 10 – 32 were summarized and divided through the number of test items to give a total-test-score for the severity of the BIID desire. For this purpose, the results of the negative formulated items (No. 10, 11, 18, 20, 22, 23, 27) were reversed. Based on this data analysis a normal distribution of the *BIID-severity* could be detected (see *Figure 1*).

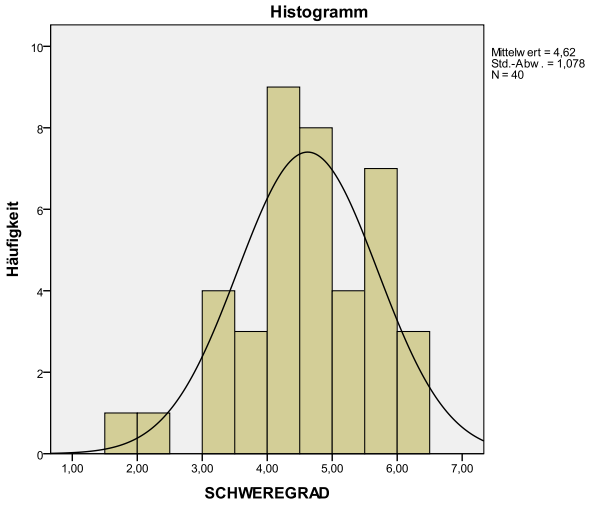

Figure 1. Distribution of BIID-severity. (Y-Axis=frequency; X-Axis=severity).

3.2. Severity of BIID

On a 7-point scale, the average total-test-score "severity" is 4,6. The minimum is 1.5 and the maximum is 6.29, the variance is 1.16 (SD = 1.078).

The classification of the severity of BIID is based on the calculated standard deviation (see **Table 3**). Using these classes, it is now possible to use the questionnaire in psychological and psychiatric practice, as well as for future studies. Due to the small sample size of n = 45, these are only preliminary normative data. The classification of the severity of BIID is shown in **Table 4**.

Table 3. Severity of BIID

Severity	
Mean	4,6226
Median	4,7857
Modus	4,43[a]
Standard Deviation	1,07768

Table 4. Classification of the severity of BIID

Severity	Mean Score	Standard Deviation
Very mild BIID	< 2,6	< -2
Mild BIID	2,6-3.5	-2 - -1
Medium BIID	3,6-5,5	-1 - +1
Severe BIID	5,6-6,5	+1 - +2
Very severe BIID	> 6,5	> +2

The hypothesis about differences between gender showed that men suffer significant stronger than women (see Table 5).

Table 5. Gender differences in severity of BIID

Statistics					
	sex	n	mean	Standard-deviation	Standard-deviation of the mean
Severity	men	33	4,5400	,80217	,13964
	women	4	3,9554	,59503	,29751

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