

Childhood Experiences with Disabilities, Hemisphere Dominance and Use of Internet Forums in Those Affected with Body Integrity Dysphoria

Diana Becker¹ and Erich Kasten^{2*}

¹Fachklinik Weibersbrunn, Hauptstraße 280, 63879 Weibersbrunn, Germany.

²Praxis für Psychotherapie und Neuropsychologie, Am Krautacker 25, D-23570 Travemünde, Germany.

*Correspondence:

Prof. Dr. Erich Kasten, Praxis für Psychotherapie und Neuropsychologie, Am Krautacker 25, D-23570 Travemünde, Germany, Web: www.erich-kasten.de, Tel. +49 157 82 81 3 555.

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ABSTRACT

Body Integrity Dysphoria (BID), previously also known as Body Identity Integrity Disorder (BIID), is a disorder in which those affected do not perceive body parts as belonging to them and often seek amputation.

***Aim:** The present study addresses the following questions: Do those affected by BID have frequent memories of contact with amputees in childhood or adolescence? Is hemispheric dominance related to the side of the need for amputation? How many affected people use Internet forums to exchange ideas with other affected people?*

***Method:** 44 people affected by BID were examined. This group was compared with a parallel sample of non-affected people in terms of age and gender.*

***Results:** The proportion of homosexuals and bisexuals in the BID group is significantly higher than in the control group. The BID group has significantly more divorced parents and significantly more amputees in their social environment, but - contrary to the hypothesis - fewer amputees among their parents in childhood and adolescence. 98% of those affected use special BID forums on the Internet. A connection between right- or left-handedness and the need for amputation on the right or left side was not found. Six patients had attempted amputation themselves.*

***Conclusions:** The data do not suggest that the need for disability was modelled in childhood.*

Keywords

Body Integrity Dysphoria, Body Integrity Identity Disorder, Xenomelia, Amputee Identity Disorder.

Introduction

"I wanted to lose both legs back then. Although I also had the feeling that my arms didn't really belong to me, it was less urgent and I didn't know how to do it or what I should do without arms and legs. When I managed to lose my right leg back then, the overall suffering was reduced. That means it's still strong enough for me to consider an illegal amputation abroad, but nowhere near strong enough for me to do it myself again!"

A female sufferer wrote this to explain her BID symptoms and the suffering associated with this disturbance. When nobody helped her, she had placed her legs on railroad tracks to force an amputation. Body Integrity Dysphoria (BID) describes a mental disorder of patients who feel a need for amputation of one of their limbs or another desire for disability in order to achieve -- from their perspective -- "completeness of their body". Usually one leg is affected, more rarely both legs or the arms [1-7]. With the entry in the new ICD-11, this diagnosis is officially confirmed [8]. Current findings suggest that BID has a neurological cause in which parts of the body are not anchored in the brain's organic representation of one's own body [9-13]. When the external body

can be successfully (most surgically) aligned with the mental body image, those affected are satisfied and usually no longer seek any further changes [14]. When people talk about BID, it has traditionally been understood that an affected person wants an amputation. However, the BID diagnosis may also include e.g. the need for blindness, paraplegia or another impairment. There are striking parallels with transidentity (transgender), who also have the feeling of living in a “wrong” body until surgical adjustment takes place [7].

Methods

Those affected by BID were surveyed using a questionnaire that was available online. Adapted from the sample of BID patients, a parallel group of unaffected people was collected. The exclusion criteria for the control group were having BID, other psychological disorders, intellectual disability, and amputation or paralysis. The exclusion criteria for the BID group were other mental disorders and intellectual disability. In the parallelization, individual test subjects were selected who were consistent with one BID patient (age, sex, and years of education). The content of the questionnaire was, on the one hand, the questionnaire “Body Integrity Identity Disorder – Screening of Severity and Intensity” by Fischer, Schnell and Kasten [15]. Questions relating to the symptoms of BID in the last six months could be answered using a seven-point Likert scale, ranging from “strongly disagree” to “strongly agree”. On the other hand, a series of self-created questions were asked, which were answered using a 6-point Likert scale. In addition, questions were asked about the dominant side of the body and the writing hand.

Participants

44 data sets from those affected by BID were usable. Details see Table 1.

Table 1: Description of BID-patients and the control-group.

	BID (n=44)	Controls (n=44)
Average age	47.98 ± 12,79	47.75 ± 13,12
Female	27.3%	25.0%
Male	70.5%	75.0%
Diverse gender	2.3%	0.0%
Not married	34.1%	25.0%
Married	47.7%	72.7%
Divorced or widowed	18.2%	2.3%
Heterosexuality	72.7%	97.7%
Homosexuality	11.4%	0.0%
Bisexuality	15.9%	2.3%
No siblings	29.5%	9.1%
1 sibling	50.0%	34.1%
2 siblings	15.9%	36.4%
3-4 siblings	2.3%	15.9%
5 and more siblings	0.0%	2.3%
Years of education	16.31 ± 3.48 y.	15.07 ± 3.87 y.
Divorced parents	29.5%	8.7%
Amputees in social surrounding	27.3%	6.8%

Six patients stated that they had attempted amputation themselves. From the group of those affected, n = 6 subjects (13.6%) would

like an amputation on the left side of the body, n = 11 on the right (25%) and n = 27 on both (61.4%) sides or a paraplegia.

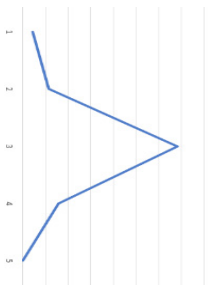
Table 2: Exact description of the BID need (data in number of participants).

BID-need	Frequency
Paraplegia	15
Amputation from right thigh	10
Amputation of both legs	6
Amputation from left thigh	4
Amputation of an arm	2
Poliomyelitis	2
One arm and one leg	1
Amputation of one leg	1
Blindness	1
Palsy of torso and legs	1
Relying on support	1

The desire for impairment was first identified by the patients themselves at an average age of about 11.14 ± 8.61 (SD) years. The minimum was 4 and the maximum was 45 years. A total of 40 patients were under 18 years of age and 24 of them were under 10 years of age when they first became aware of their BID disease. The score of the screening of severity and intensity by Fischer, Schnell and Kasten [15] showed an average score of 2.95 ± 0.68 (SD), with the minimum of the test being 1 and the maximum is 5. The distribution of the frequencies is shown in Table 2 and roughly follows a normal distribution [16].

Table 3: Characteristics of the severity of BID symptoms.

Severity of BID	Frequency
1 = Very mild (<2.6 points)	4.5%
2 = mild (2.6 -3.5 points)	11.4%
3 = medium (3.6 – 5.5 points)	68.2%
4 = strong (5.6 – 6.5 points)	15.9%
5 = very strong (>6.5 points)	0%



Only one person in the control group was not in a relationship, but eight people in the group of BID patients reported this. With a slight effect, those affected by BID were significantly more likely to be without a relationship (p = .014) compared with the control group. When asked whether the illness made them feel special, 36.4% (n = 16) answered “no”, 29.5% (n = 13) said that it made them feel “special” in a positive and 34.1% (n = 15) find this in a negative sense.

When asked whether they would like to wear a prosthesis after the operation or are already doing so, 31.8% (n = 14) answered no, 25% (n = 11) would like to wear one permanently, 22.7% (n = 10) occasionally and 20.5% (n = 9) do not yet know this exactly. Among the 44 respondents, there were two subjects (4.5%) who already had achieved a successful surgical amputation. At the age of 22, one patient's wish changed from an amputation of the right thigh to a paraplegia. One patient had a self-amputation by placing her legs on railroad tracks until a train came (see introduction). The

plan was to get both legs amputated, but because the train threw her to the side, only the amputation of one leg was successful. This person would like to have the other leg amputated, too. According to her own statements, their level of suffering has reduced after the amputation, but is still significant, so the person concerned is considering an illegal amputation abroad. Furthermore, one patient (2.3%) stated that he did not long for BID in the “classic” meaning, but rather that his wish was expressed in the sense that he would like to have his physical functions restricted, so that this could only be achieved to some extent with adequate care and assistance of a helpless person. Affected regions of this subject include the eyes, ears, teeth, skeletal system and bladder function. One patient stated that the severity of his BID depends heavily on his daily form. He hardly feels the need when everything is relaxed, but very strongly when he experiences a lot of stress in a relationship or at work, for example. His BID desire is very dominant when he meets people with disabilities or sees photos or videos of them, for example on the Internet. The questionnaire asked whether one feels impaired in one's sexual life due to the consequences of BID. On a scale from 1 “strongly disagree” to 7 “completely agree”, an average of 4.5 was given with a standard deviation of 0.27.

Results

The assumption that BID patients are significantly more likely to have a parent with a missing body part could not be confirmed. Contrary to assumptions, in the here presented data it was shown that with a significance of $p = .012$ the controls are more likely to have parents with missing limbs than BID patients. The value regarding the fathers is particularly significant with $p = .042$ ($r = .217$). There was also no significant difference between the BID and the control group in the grandparents' generation ($p = .40$). Of the 44 BID patients surveyed, two had family members from their parents and grandparents who were missing a body part. One subject's maternal grandfather had lost toes in the war. The test person perceived this as positive. The other participant's paternal grandfather had no right arm. In the control group, eight people (18.2%) stated that their parents and grandparents had family members with missing body parts. These were distributed among four fathers, a mother, two maternal grandfathers and a paternal grandfather. Seven of the respondents said that one missing body part of a relative were fingers and for one it was the mother's amputated breasts. With a value of $p = .011$ it was shown that there is a significant difference with a small effect size of $r = .270$ in how many amputees are known to BID patients compared to the control group. Naturally, those affected by BID know more amputees through Internet forums. The questionnaire asked about Internet usage behavior using three questions. The frequency of use of BID-related forums varied greatly. 9.1% ($n = 4$) used the forums little, 20.5% ($n = 9$) rather little, 13.6% ($n = 6$) partly, 13.6% ($n = 6$) rather often, 25% ($n = 11$) frequently and 18.2% ($n = 8$) very frequently. The answer “not at all” was stated by none of the respondents. When asked how active or passive they are in corresponding forums, 2.3% ($n = 1$) said passive, 34.1% ($n = 15$) said they were rather passive, and 22.7% ($n = 10$) said they were partly passive, 25% ($n = 11$) were rather active and 15.9% ($n = 7$)

active. No significance could be demonstrated for the assumption that the use of forums is more frequent depending on the severity of the BID. However, it was shown that the activity in the chat forums had a significance of $p = .035$ according to the BIID score value measured by the questionnaire by Fischer, Schnell and Kasten [15]. If one looks at the desire for amputation and for paraplegia separately, it can be seen that the 15 subjects (34.1%) who would like to be paraplegic, are more often in Internet forums than the 24 test subjects (54.5%) who would like an amputation ($p = .006$, effect size of $r = .44$). Most BID people recognize the exchange with other affected people as helpful and receive tips on how to deal with the need to be disabled. On the other hand, one patient described the participation in such forums as follows: *“I usually experience visiting BID forums as something rather 'toxic' - a bit like the corner bar for the alcoholic. I have searched in vain for a group of people who had an interest in combating the disease BID rather than eliminating it through mutilation.”*

Overall, the group of BID patients was divided into 42 (95.5%) right-handers and two (4.5%) left-handers. The control group consisted of 39 (88.6%) right-handers, four (9.1%) left-handers and one (2.3%) ambidextrous person. When asked which side of the body was their dominant side, 15.9% ($n = 7$) of BID patients said the left side of the body and 61.4% ($n = 27$) said the right side of the body. 22.7% ($n = 10$) of respondents said that neither the left nor the right side were their dominant sides of the body. 81.8% ($n = 36$) of the control group had a dominance of the right side. The hypothesis that there is a connection between the dominant side of the body and the side of the body on which the amputation is desired could not be confirmed ($p = .407$). For this calculation, only the 17 (38.6%) subjects who wanted a unilateral amputation were taken into account. Imitation of the disability was performed by 42 of the 44 BID sufferers (see Table 4).

Table 4: Imitation of the disability (“pretending behaviour”) as coping mechanism.

Pretending hrs per day	<1	1-2	2-4	4-6	6-8	8-10	10-12	>12
Number of patients	14	9	9	4	1	0	4	1

Discussion

It was found that, contrary to what was expected, BID patients actually had fewer close family members with amputated limbs than the control group. This probably suggests that a family component in the form of model learning in childhood is not necessary for the disease to occur patients often see pretending behavior as an opportunity to visually come as close as possible to their desire for amputation and thus maintain their subjectively ideal body image for a certain period of time. However, there is also another aspect of pretending, which one test subject describes as follows: *“I have suffered from BID since childhood and will only truly be “myself” when I can no longer feel or move anything, at least below my chest. As you get older, the pressure becomes more and more unbearable. I often visualize being paraplegic, but I don't pretend. Pretending makes my suffering even worse because I can still feel and move my whole body, which is even*

harder for me to bear when pretending than in everyday life.” This aspect shows that pretending is not only a way to help people adapt to their body ideal, but also that it can make it clear to those affected that their body’s ideal is only temporary and they have to return to their suboptimal appearance after a certain time. This can be associated with a high level of suffering.

The hypothesis that there is a connection between the dominant side of the body and the side of the body on which the amputation is desired could not be confirmed ($p = .407$). For this calculation, only the 17 (38.6%) subjects who wanted a unilateral amputation were taken into account. However, of the 44 respondents, 27 (61.4%) were unable to specify a side of the body because they wanted either a bilateral amputation or a paraplegia and therefore could not be included in the calculations. This data is therefore only based on the information provided by 17 people affected by BID (38.6%, including 13.6% on the left and 25% on the right).

Despite the dissatisfaction caused by the discrepancy between the intact external body and the mental body representation of a disabled person, not all those affected by BID strive for amputation. A large proportion feel the need to be paralyzed, even becoming paraplegic. But even the group that feels that one leg is too much on the body often does not immediately seek surgery. As the survey about the strength of BID shows, the level of suffering is rather low for some of those affected. One BID patient interviewed stated that he was afraid of losing friends if he had surgery. This aspect certainly has a major influence on the desire to have an amputation and on whether one pretends in everyday life. In addition to autonomy, the circle of friends and acquaintances as well as one's own family are important and most likely influence decision-making [17]. In addition to a more emotional aspect, the financial aspect also plays an important role in the decision for or against an operation. A patient describes that for financial reasons he has no opportunity to have an operation abroad and because of this he tried to tie off his leg to force an amputation, but failed. The puzzle of the disease remains very incomplete and many scientific questions remain unanswered. It is clear that many of those affected are suffering greatly and need our help.

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