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Estimation of the Prevalence of Body Integrity Dysphoria (BID) in German-Speaking Countries Based on the Use of an Internet-Forum by Those Affected

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Abstract

Body Integrity Dysphoria (BID, BIID) is a disease of unknown cause, in which those affected have the intense feeling that a part of the body does not belong to them. BID-sufferers can feel and move the corresponding limb, but it is not part of their mental body image. Estimating the prevalence of BID is very difficult due to the fact that most sufferers do not confide their suffering to anyone. However, the situation has changed since the widespread use of various Internet platforms. The basis is that in the three German-speaking countries (Germany, Austria, Switzerland) most adults have access to the Internet and, sooner or later, are looking for information about the strange feeling that parts of the body don't feel like they belong. It can therefore be assumed that many of those affected will at some point register in such a forum in order to exchange ideas with others. The quantities are estimates from: (a) Number of BID affected people in the German speaking BID-DACH forum, (b) Number of BID affected people registered in BID forums in the German speaking areas, (c) Number of those affected by BID who do not register but inform via social media, (d) Estimation of the total number of people affected by BID from (a), (b) and (c). According to this model, the prevalence is in the range of 1 in 5,500 (0.018%) to 1 in 22,000 (0.0045%), mean value is in the range of 1 in 11,000 (0.01%). According to the data from Fischer et al (2015) and Garbos et al (2022), the severity of BID follows a normal distribution. This means that 16% have a very mild form, they feel relatively little pressure and they are often probably not even aware that they are suffering from BID at all. The middle 68% from a statistical perspective have a moderate form of BID. Most achieve sufficient catharis with occasional pretending and often do not seriously pursue real disability. Serious candidates for an amputation or other forms of disability are those with an above-average level; they include the top 16% of the distribution. Of these 1,500, around half suffer from the need for amputation, the other half have a desire for paraplegia or other forms of disability. Here it is to be expected that they will want an operation in the long term. This value can be justified rationally, because every realization of the need for disabilities is associated with massive restrictions in everyday life. Those affected are well aware of these limitations and even in the group of severe cases, most people delay it for decades before giving in to the need and having an operation (or other options) carried out. If we assume that the 750 people ready for amputation are spread across the age group 20-70 years, after processing the backlog of old cases, then a maximum of 15 new candidates for amputation per year would be expected. This model refers to the German-speaking area because the forum is conducted in German. However, it seems entirely permissible that a similar prevalence value can also be assumed for several other countries.

Keywords: BID: Body integrity dysphoria; BIID: Body integrity identity disorder; Prevalence.

Introduction

A very small group of people with intact bodies feel the need to have a disability [1]. This disturbance is named as Body Integrity Dysphoria (BID, former Body Integrity Identity Disorder = BIID), it is a disease of unknown cause. A multi-causality of genetic, neurological and psychological influencing factors is assumed, in which those affected have the intense feeling that a part of the body does not belong to them. BID-sufferers can feel and move the corresponding limb, but it is not part of their mental body image. The disorder usually causes severe psychological distress, so that many people try to amputate this part of the body, others are forced to use a wheelchair because they do not feel that the lower half of the body belongs to themselves. First and co-authors [1,2] have found that many BID sufferers have undergone surgery to adjust the appearance of their real body to their mental image.

Initially, the symptoms were termed e.g. as Apotemnophilia, Xenomelia, "wannabes", Amputee Identity Disorder, or Body Integrity Identity Disorder (BIID). The disorder's inclusion in the [19] *International Statistical Classification of Diseases and Related Health Problems* (11th ed.; *ICD-11*) and the American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5)* has made a renaming to *Body Integrity Disorder* (BID).

In the chapter 6C21 the ICD-11 describes this need to be disabled as: Body integrity dysphoria is characterized by an intense and persistent desire to become physically disabled in a significant way (e.g., major limb amputee, paraplegic, blind), 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 (including time spent pretending to be disabled) significantly interfering with productivity, with leisure activities, or with social functioning (e.g., person is unwilling to have a close relationships because it would make it difficult to pretend) or by attempts to actually become disabled have resulted in the person putting his or her health or life in significant jeopardy.

The condition usually develops in childhood or early adolescence and often represents a perceived need that extends across the patient's entire lifespan [1]. The predominant focus of this desire for disability is the amputation of a limb [1]. However, it may also involve a loss of sensory capabilities, such as blindness, deafness, or paralysis [3]. 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 "over complete" [1].

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; [2]). People with BID call these behaviours *pretending* [20]. Dissatisfaction with the body can increase to the extent that they go to radical methods, such as freezing limb tissue in dry ice, triggering infection, or amputating by placing the limb on railway tracks [4,5]. Alternatively, those with BID may seek surgery, which may be illegal in most countries [20].

A study carried out in 2014 by Noll & Kasten [17] found that 23.8% of the successful BID sufferers did not feel the need for amputation of a body part but other disabilities. Interestingly, individuals with a need for blindness showed exaggerated responses to visual stimuli and consequently perceived visual impairment as more relaxing [6,7] 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.

McGeoch and co-authors [16] investigated four BID-Patients. Their model said that the right superior parietal lobe is a cortical area that unifies disparate sensory inputs to create a coherent sense of having a body. The authors propose that inadequate activation of the right parietal lobe leads to a situation in which the sufferers are unable to incorporate a limb into their body image, this results in a desire for amputation. The authors introduced the term 'xenomelia' (xeno=alien, melia=limb). While until then BID had been assumed to have psychological causes, this led to BID now being seen as a neurologically based disease [8].

Saetta et al. examined 16 patients who felt a need for a removal of the left healthy leg [18]. The primary sensorimotor area of the to-be-removed leg and the right superior parietal lobule were less functionally connected to the other brain structures. The left premotor cortex, which is involved in the multisensory integration of limb information, and the right superior parietal lobule were atrophic. The more atrophy, the stronger the desire for amputation, and the more an individual pretended to be an amputee by using wheelchairs or crutches to solve the mismatch between the desired and actual body. The findings of these authors illustrate the important role of the connectivity of different brain areas for the feeling of body ownership. They help to understand the experience of body and self as a seamless unity.

In another study Gandola et al. [15], used fMRI to evaluate whether these findings could be replicated. These authors measured brain activations during somatosensory stimulation and motor tasks in ten BID-patients with a need for the amputation of the left leg and fourteen controls. BID individuals had reduced brain activation in the right superior parietal lobule for somatosensory stimulation and in the right paracentral lobule for the motor task. In addition, they found a reduction in activation of somatosensory areas bilaterally. Gandola et al. conclude that BID is associated with altered integration of somatosensory and motor signals in brain regions where the first integration of body-related signals is achieved through convergence.

Saetta et al. published another study in 16 men with BID with a long-lasting need for left leg amputation [9]. In this work these authors aimed to identify altered patterns of white matter structural connectivity. Fractional anisotropy was considered as a measure of structural connectivity. Results showed reduced structural connectivity of the right superior parietal lobule with the right cuneus, with the superior occipital and with the posterior cingulate gyri. In addition, the pars orbitalis of the right middle frontal gyrus was less connected with the putamen; and the left middle temporal gyrus with the pars triangularis of the left inferior frontal gyrus. On the other hand, increased connectivity was found between the right paracentral lobule and the right caudate nucleus. These findings consolidate the current understanding of the neural correlates of the amputation variant of BID.

With BID now included in international disease classifica-

tions (ICD, DSM), in long-term doctors and hospitals must provide also treatment as it is now an officially recognized disease with suffering. One of the most important questions is: What are the costs for health insurance companies? What, for example, an amputation costs, is clearly regulated. But the key question is: How many BID sufferers are there actually?

This question is not easy to resolve because BID is a disorder that causes embarrassment to those affected. Crutches and wheelchairs for pretending are shamefully hidden. Many people travel to distant cities to walk on crutches or sit in a wheelchair and hope not to meet anyone who knows them. Even immediate family members usually do not know that their relative feels a need for amputation or paralysis. They also rarely appear in practices of doctors or psychotherapists. It is therefore extremely difficult to find clear data on the number of people affected. The only place where those affected by BID show up and seek advice and help (often using a pseudonym) is on the Internet.

Epidemiological studies are very complex due to the small number of people affected. Most publications therefore succinctly point out the fact that we actually don't know how many people affected by BID there really are. A wide range of prevalence assumptions can be found in the literature, e.g. The Lancet Psychiatry published a comparison with BDD (body dysmorphic disorder) with a prevalence of around 2%, while in one publication "An overwhelming desire to be blind" [6] is spoken of "several thousand people worldwide". There are several powers of ten between these statements.

However, the situation has changed since the widespread use of various Internet platforms. Relevant forums, chat rooms, etc. for BID have developed and offer those affected the opportunity to exchange information. Since that time, attempts have been made to derive a prevalence of BID from the use of these forums.

In 2010, the BID-DACH forum [https://www.bid-dach.org/] was established, which even uses a questionnaire for the internal part of the forum ("members area") in order to be able to more accurately identify those affected. There are currently around 1,300 members in this forum. The BID-DACH Forum has achieved a special status as a German-speaking forum because, with a few exceptions, the circle of participants is limited to the D (Deutschland=Germany), A (Austria=Österreich) and CH (Confoederatio Helvetica=Switzerland=Schweiz) areas and almost exclusively speak German as their native language.

The present work therefore attempts to derive the prevalence of BID based on the BID-DACH forum.

Theoretical basis

The basis is that in these three German-speaking countries most adults have access to the Internet and, sooner or later, are looking for information about the strange feeling that parts of the body don't feel like they belong. This is especially true since the associated suffering often is very high. It can therefore be assumed that those affected will at some point register in such a forum in order to exchange ideas with others. From our point of view, the fact that this is mainly done using a pseudonym does not affect the data situation. The calculation presented here is based on the hypothesis that the use of the BID-DACH forum and subsequent assumptions about social media usage behaviour form a sufficient basis for calculating a reliable estimate of the prevalence of BID. Although this estimate will still be uncertain, it should be sufficient to at least represent a plausible range of the prevalence of BID.

Methodology

The methodology is based on a deduction in several steps, starting from the number of members of the BID-DACH Forum, each deduction step creates a superset of the previous set.

The quantities are estimates of:

(a) Number of BID affected people in the BID-DACH forum

(b) Number of BID affected people registered in BID forums in the D-A-CH area

(c) Number of those affected by BID who do not register but inform via social media

(d) Total number of people affected by BID from (a), (b) and (c).

The process of decomposition into several steps makes it possible to arrive at a value that can be better argued for than a general global estimate of those affected by BID (e.g. from comparisons with other illnesses or dysphoriae). Each of the steps can be calibrated and (to a certain extent) plausibly checked, so that probable and less probable assumptions can be separated.

Calculation model

This section describes the deduction steps in detail. The specific numbers for estimating the individual parameters are summarized in a table below.

1st step (registered BID affected people in the BID-DACH forum)

The starting point is the number of members in the BID forum (as of April 27, 2022: 1,282). With a few exceptions, the members come from the D-A-CH area (Germany, Austria, Switzerland). The age group roughly includes young people and adults between the ages of 10 and 79. If all non-affected people (e.g. relatives), some onlookers and fake members that can be expected despite best efforts are taken into account, a large number of members remain who will be listed as true BID affected in the following. Ultimately, it is considered rather unlikely that a person who does not suffer from BID will register in this forum and take part in the discussions.

Whether the dysphoria is more or less pronounced in these BID sufferers is not differentiated here. With a few exceptions, the assignment to those affected by BID is based on the self-assessment of having BID and not on a medical report, which creates an unavoidable uncertainty. On the other hand, the life and suffering stories of those affected by BID are considerably similar - so that many people affected by BID can, even as laypeople, reasonably reliably assess themselves correctly. Ultimately, however, it are those who really suffer from BID who exchange their thoughts in such a forum.

The estimate on this first step is the number of registered members in the BID-DACH forum that are actually affected by BID.

The lower limit of the plausible values is assumed to be that, despite answering the questionnaire, only 30% of the currently registered members can actually be counted as BID affected. An analysis of the member list suggested that the upper limit could be assumed to be around 50%. All other members would

either be relatives, from outside of European German speaking countries or interested but not affected.

2nd step (share of the BID-DACH forum in all registered BID affected parties, including other forums/platforms)

In addition to the BID-DACH forum, there are other social networks, platforms or forums where those affected by BID can register and exchange ideas in communities. The BID-DACH forum therefore has a certain "market share" of registered users with BID. By estimating this proportion, one can draw conclusions about the total number of all those affected by BID in D-A-CH (Germany, Austria, Switzerland) who are registered in the currently available web platforms related to BID.

One can assume that the BID-DACH Forum has a high market share, i.e. that a high proportion of all those affected by BID in the D-A-CH area have chosen the BID-DACH Forum as a platform for the exchange of information. This is supported by the long availability (since 2010), the entry hurdle (questionnaire to be answered), the prescribed rules of conduct and the stringent moderation. This creates a high-quality source of information and a serious communication culture that hardly any other German-speaking forum offers. Those affected by BID who obtain information on the Internet are familiar with the large number of unmoderated or barely moderated platforms, which are characterized by often questionable participants and contributions and which therefore do not appeal to those who are seriously looking for an exchange due to their suffering.

The estimated value of this step is the "market share" of the BID-DACH forum in all forums or web-based communication platforms that offer registration.

The lower limit of the plausible values is assumed to be that 50% of all those affected by BID in the German speaking D-A-CH area are registered in the BID-DACH forum. The upper limit is 80%. All other BID affected people are registered in other forums or social media channels.

From this estimate, in conjunction with the estimate from step 1, it can be calculated how many BID affected people have actually registered on the web in at least one of the existing offers.

3rd step (unreported number of people affected by BID who are not registered but use the internet)

Despite the anonymity offered, registering in a forum or a social media platform is a barrier to entry that many BID sufferers shy away from. There are therefore many affected people who get information on social media but would never register.

There is no reliable basis for estimating this number of unreported cases. It is generally assumed that the number of unreported cases is high, i.e. the number of unregistered BID sufferers is many times higher than the number of registered ones.

The estimate of this step is the number of unregistered BID subjects in relation to those registered in at least one of the web platforms.

The lower limit of the plausible values is assumed to be that for every registered person there are around three non-registered BID sufferers. The upper limit is assumed to be that there are around five non-registered BID sufferers for every registered person.

4th step (number of internet users using social media)

From various studies on the use of social media, we know quite precisely how social media is used by the general population. There are significant differences depending on the age group.

Calculated across the 10 to 79 age group, it can be assumed that in Germany about one in two people use social media at all (see https://blog.hubspot.de/marketing/social-media-in-deutschland from 2020, where the proportion of the entire German population is given as around 45%, including messenger services). The age groups of those aged 10 and over and those aged 80 and over were excluded because there are hardly any people affected by BID in the BID-DACH forum who fall into these age groups and the assumptions made here can no longer be applied with sufficient accuracy in these groups for various reasons.

The estimate of this step is the proportion of the population using social media in the total population. With reference to the literature, the proportion is assumed here to be 50%. This proportion will also apply to that part of the population with BID (i.e. every second BID-sufferer).

The affected person does not use social networks at all and can therefore not have been included in the previous analysis.

Calculation of the number of people affected by BID

The following table summarizes the calculation mentioned above and the resulting estimation range:

Table 1: Estimation depending on the number of people in the german-speaking BID-DACH-Forum.

Step of estimation	Estimation range	Absolute values
1) BID affected people in the BID-DACH forum (base 1,278). Percentage is the proportion of members of the BID-DACH forum who can be considered as BID affected.	30%-50%	383-639
(2) "Market share" of the BID-DACH Forum	50%-80%	479-1,278
3) Unreported number (number of non-registered users per registered user)	3 – 5 unregistered subjects for one registered	1,917-7,668
4) proportion using social media	50%	
Total number of people affected by BID		**3,834-15,336**

Table 2: Estimation depending the average of the number of people in the German-speaking BID-DACH-Forum.

Step of estimation	Average of the estimation range	Absolute values
1) BID affected people in the BID-DACH forum (base 1,278). Percentage is the proportion of members of the BID-DACH forum who can be considered as BID affected.	40%	511
(2) "Market share" of the BID-DACH Forum	65%	786
3) Unreported number (number of non-registered users per registered user)	4 unregistered subjects for one registered	3,932
4) proportion using social media	50%	
Total number of people affected by BID		**7,864**

Calculation of the reference quantity of the population

The reference quantity is the proportion of the population from D-A-CH that fits the above statements, i.e. all residents of the three countries in the age group 10 to 79 years.

Table 3: Estimation of the reference population of the german speaking countries.

	Germany	Austria	Switzerland	Total
Population (million inhabitants)	83.24 Mio	9.00 Mio	8.64 Mio	100.88 Mio
Under 18 or over 79 years of age	14.00 Mio	1.39 Mio	1.22 Mio	16.61 Mio
Reference set	69.24 Mio	7.61 Mio	7.42 Mio	**84.27** Mio

Prevalence estimation

The figures derived above provide the following estimates for the prevalence of BID.

Table 4: Estimation of prevalence in the German speaking countries.

	Lowest estimation	Highest estimation	Average
Absolute number of BID affected	3,834	15,336	7,864
Reference population		84,27 Mio.	
Estimation of prevalence	1 out of 21,980 (i.e. 0.005%)	1 out of 5,495 (i.e. 0.02%)	1 out of 10,715 (i.e. 0.01 %)

The estimation of the prevalence results in a range between 1 in 5,500 to 1 in 22,000 inhabitants or 0.005 to 0.02%. It can be supposed as unlikely that the actual prevalence lies outside this range. Choosing the mean value of the individual parameters results in a prevalence estimate of around 1 in 11,000 or 0.01%

Estimate of the total number of affected people in D-A-CH

The estimation of the prevalence in the three German speaking counties is shown in Table 5.

Table 5: Estimation of prevalence in the german speaking countries.

	Germany	Austria	Switzerland	total
Population	83.2 Mio	9.0 Mio	8.6 Mio	100,8 Mio
Lowest estimation	3,787	409	393	4,590
Highest estimation	15,149	1,638	1,572	**18,359**
Average	7,768	840	806	9,415

However, this number includes both mild and moderate and severe cases of BID. Body Integrity Dysphoria, like most other disorders, is not equal in severity. Some of those affected do suffer from it, but often only in phases and many never plan to actually carry out an amputation or actually acquire another disability. Others suffer so much that, in desperation, they put their feet on railway tracks and wait for the next train. According to the author's experience, who has now met over 100 affected people and examined many of them, and according to the data from [10] and [11], the severity of BID follows a normal distribution. This means that 16% (1,500 patients) have a very mild form, they feel relatively little pressure and they are often probably not even aware that they are suffering from BID at all. The middle 68% (6,400 patients) from a statistical perspective have a moderate form of BID. Most achieve sufficient catharsis with occasional pretending and often do not seriously pursue real disability. Serious candidates for an amputation or other forms of disability are likely to be those with an above-average level; they include the top 16% (1,500 patients) of the distribution. It is to be expected that they will want an solution of their need for a handicap in the long term. The author believes that this value can be justified rationally, because every realization of the need for disabilities is associated with massive restrictions in everyday life. Those affected are well aware of these limitations and even in the group of severe cases, most people delay it for decades before giving in to the need and having an operation (or other options) carried out.

Discussion

The model presented here compares the previous global estimates of the prevalence of BID with a multi-stage extrapolation model. The procedure is based on the evaluation of the number of members from the BID-DACH forum and assumptions and surveys on the use of the Internet and social networks. This and the relatively good geographical delimitation of the reference quantity to the D-A-CH area results in a concrete, calcula-

ble basis for estimating the prevalence. The influence of other parameters that are difficult to access, such as the number of unreported cases, on the result is smaller.

According to this model, the prevalence is in the range of 1 in 5,500 (0.018%) to 1 in 22,000 (0.0045%), and - taking the mean values of the individual parameters in the range of 1 in 11,000 (0.01%). According to our experience, only the top 16% above average really will perform an operation. Of these 1,500, around half suffer from the need for amputation, the other half have a desire for paraplegia or other forms of disability. If we assume that this prevalence of 750 people looking for surgery are spread across the age group 20-70 (i.e. 50 years) then, after processing the backlog of old cases, a maximum of about 15 new candidates per year would be expected for an amputation of a limb.

According to international comparative studies on amputations [12,13], Germany is in the highest quartile with 9.2 major amputations per 100,000 people per year. The OECD average is 6.4 major amputations per 100,000 people per year. This means that based on the reference value of 84 million, this is around 7,700 major amputations per year. Therefore, about 15 BID-related amputations per year would only increase this value by 0.2%.

BID is often compared to transgender (transsexuality, gender identity disorder) both are disorders of one's body identity. As with BID, transgender people's innate body is not perceived as correct. Both disorders begin in childhood and adolescence and show striking parallels. In particular, the aim is usually to surgically align the external body with the mental representation of the body in the brain. 2,598 people had gender reassignment surgery in Germany in 2021. Transwomen (i.e, men to women) account for two thirds of the procedures. The majority of procedures were performed in the age group 20 to under 35 years [14]. BID therefore appears to be significantly lower than gender identity disorder. However, our society tolerates transgender people and helps those affected to have gender reassignment surgery at the expense of their health insurance companies. The much smaller group of BID sufferers, who have the feeling that a limb does not belong to them, do not benefit from such services, but are currently still having to seek help in foreign clinics for large amounts of money.

The model refers to the German-speaking area because the BID-DACH forum is conducted in German. However, it seems entirely permissible that a similar prevalence value can also be assumed for several other countries (e.g. the EU area, England, USA, Canada, Australia).

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