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Review Article

The Lame Who Can Walk and the Blind Who Can See – Are People with Body Integrity Dysphoria Severely Disabled?

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Abstract

Goal: The main question of the study is whether someone should receive an official confirmation as a severely disabled person, even though this person does not actually have a disability, but simply does not want to walk for psychological reasons? Body Integrity Dysphoria (BID) encompasses the desire to have a disability, e.g. to have a paraplegia, to be blind, to be deaf or to have a limb amputated. Only with this disability those affected feel "complete". BID was integrated into version 11 of the International Classification of Diseases (ICD) in 2022, this will raise legal and administrative questions.

Method: A survey of 49 people affected was carried out for this purpose. The data were compared with a parallelized group of patients who had received a degree of disability due to a real physical disorder.

Results: 34 of those affected by BID stated that they had made the diagnosis themselves, i.e. only a small proportion had a well-founded medical diagnosis. Of those affected by BID who had an official disability card (n = 13), however, only six stated to have a disability ID solely because of the Body Integrity Dysphoria disease.

Conclusions: Current research suggests that BID is a congenital neurological malfunction in the brain; affected patients suffer greatly from this disorder. They are not to blame; it's not that they don't want to walk, but rather that they are psychologically unable to move. At least some government agencies recognize this and actually grant those affected recognition as severely disabled.

Keywords: Body Integrity Dysphoria; Body Identity Integrity Disorder; Degree of Disability; Confirmation as Severe Disabled

Introduction

A patient is confined to the use of a wheelchair and complains that the responsible office has not assigned him a degree of disability. He believes that, since he is wheelchair-bound, he is entitled to a degree of disability of at least 80% and the "G" symbol for not being able to walk. However, the employee in the Social Affairs Office refuses, as he believes the patient is, in principle, perfectly capable of walking; he just doesn't want to. Or, more precisely, he can walk, but he has an intense need to be in a wheelchair. Is someone like that entitled to a degree of disability? However, the patient feels an urgent need to do his work from a wheelchair and he wants proof of disability because his company already had hired him as a disabled person.

Definition of disability

According to the Social Code, persons are considered to have a "disability" if they have physical, mental, or intellectual impairments. In interaction with attitudinal and environmental barriers, there must be a high impairment of social participation over a longer period of time (in Germany of at least six months [1]). Such an impairment exists if bodily functions and health status deviate from the typical state for the age. Not only visible disabilities are relevant; even an invisible disability such as a mental or psychological illness (e.g. schizophrenia or depression) can be considered. Most western countries use different scales to assess the severity of a disability, but a scale from 0 to 100 has become the most common in many countries (see Table 1).

For example, under German law, complete paralysis of both legs results in a degree of disability of 100, as does total blindness. Partial paralysis of the legs with residual function results in a degree of disability of approximately 80. Complete deafness results in a degree of disability of 100, and one-sided deafness results in a degree of disability of approximately 70, if the other ear is also hard of hearing. The amputation of one leg from mid-thigh onwards reduces the degree by between 80 and 100, while amputation of both legs again results in a degree of disability of 100. The loss of an arm is rated at 70, and the absence of a hand at 50. In Germany, psychological difficulties, such as depression due to the illness, do not increase the degree of disability. The office assumes that every severely disabled person suffers from psychological consequences, i.e., depression is already included in the degree. The picture becomes more complex if someone was already depressed before acquiring a physical disability. Depending on the severity of the depression, the rating ranges from zero to 100.

Country	Term	Scale	Severely disabled from a degree of...
Austria	Degree of Disability	0–100	^{3}50
France	Taux d'incapacité permanente	0–100	^{3}80
Germany	Degree of Disability	0–100	^{3}50
Switzland	Degree of Invalidity (Incapacity to work)	0–100	^{3}40: partial pension, ^{3}70: full pension
USA	Disability Rating (Veterans)	0–100	From 10%: partial claims to 100%: full support

Table 1: Examples of types of classifications of patients in the disability scale.

In Germany, if the degree of disability (GdB) is between >0 and <50, the person is "disabled"; if the degree of disability is 50 and more, the patient is considered "severely disabled". In such a case, a severely disabled person's ID card can be applied for; the corresponding symbols will then be entered if necessary, e.g., "G" for "walking impaired," "aG" for exceptional walking impairment, or "H" for "helpless". To receive the degree of disability and thus an ID card, the affected person submits an application. The authorities responsible for implementing the Federal Social Security Act determine the existence of a disability and the degree of disability at the time of application (Social Code). The application is usually assessed in cooperation with medical experts. In Germany the basis is the use of the so-called "GdB table" ("Grad der Behinderung"). This table is used to classify the existing illnesses. The effects on participation in social life are graded and recorded as a degree of disability in increments of ten. If multiple impairments are present, the impact of individual functional impairments is weighed and the corresponding degree is recognized. According to the German law, the most significant disabling condition is fully assessed, while other conditions are then only assessed at a decreasing fraction, so that the total degree of disability can never exceed 100%. The card serves as proof of the use of services and other assistance to which severely disabled people are entitled. The validity period can be limited if improvement is possible, or

unlimited if no cure is expected. The card is corrected as soon as a new assessment becomes necessary. If companies hire a disabled person, in Germany the corresponding compulsory contribution is reduced. Depending on the country, other advantages are e.g.: compensation for disadvantages, job protection, tax advantages, protection against dismissal, additional vacation, disability pension, retraining, pension, medical benefits and medical aids [1].

Body integrity dysphoria

The patient in the example from the introduction would like to have a degree of disability and the G symbol because he is in a wheelchair and cannot walk. However, he could walk if he really wanted to. He does not have true paralysis; he has been in a wheelchair for several years due to psychological reasons. His legs are physically healthy (except for the beginning of muscle atrophy due to his refusal to use his legs), but moving around on two legs does not correspond to his mental image of himself. His mental image in his brain tells him that his legs do not belong to his body. He could use them, but then he would violate his mental body image, which tells him that he is actually paralyzed.

Body Integrity Dysphoria (BID, formerly known as Body Integrity Identity Disorder = BIID) is a very rare disorder with an estimated prevalence of 0.01% affected people [2]. This disorder is characterized by a lack of identification with specific body parts. People with BID feel that a part of themselves doesn't truly belong to their body [3-7]. Often, there is a strong urge to align their physical appearance with their mental image of their own body, for example, by amputating a leg. Only without this body part do those affected feel "complete". In rare cases, BID can also manifest itself in the desire to lose a sense, such as sight or hearing [8].

In Germany, ethical and moral reasons currently speak against a surgical solution. Surgeons have so far refused to remove an intact body part, thus creating a disability, just because the patient wants it. On the other hand, there is a psychological indication that favours amputation, as the suffering of having to live in a body that does not correspond to the mental image of one's own body can be considerable [9,10]. Sometimes, those affected even perform dangerous acts on themselves to achieve the desired physical condition or to force doctors to amputate the body part in question (e.g. freezing a leg in dry ice).

To remedy this lack of identity, those affected usually initially use wheelchairs, crutches, orthoses, or prostheses. Since many people with BID spend their lives in wheelchairs, they desire to be treated the same as a patient with a real physical disability. They want all the rights to which a person with a physical disability is entitled. Therefore, an increasing number of people with BID are applying for disability certificates.

There are no doctors worldwide who surgically damage visual acuity, deafness, or make a paraplegia. Those with BID who desire paralysis simply no longer use these body parts. Those requiring amputation are somewhat better off, as there are doctors who can amputate even a physically healthy leg. Clinics in developing world countries, in particular, do perform such operations for cash. However, the true reason for the lost limb is usually concealed; instead, those with BID invent, for example, an accident or a supposed septic infection, during which the leg "unfortunately" had to be amputated. They usually obtain the degree of disability for such an amputation from the responsible authorities without any problem, since they – understandably – do not reveal the true reason, and the amputated body part is really no longer there.

More problematic are those affected who pretend to be paraplegic with crutches, orthoses, or in a wheelchair, yet still retain the rejected body parts. Individuals with a desire for paraplegia, blindness, or deafness can, in principle, walk, see, or hear. However, when healthy, they are not only out of sync with their mental body image; they suffer like a normal person whose body image is programmed to be "slim," but who weighs 150 kg and feels ugly looking in the mirror.

Most individuals with a desire for paraplegia spend almost all of their waking hours in a wheelchair, thus gradually causing increasing muscle atrophy through the permanent disuse of their limbs – often to the point where they are actually no longer able to walk long distances or even stand on their own two feet. The question is whether they can be assigned a degree of disability for such a "self-inflicted" disability?

Starting in January 2022, Body Integrity Dysphoria (BID) was officially listed as a disorder in the 11th version of the International Classification of Diseases (ICD-11). This will increasingly allow those affected to submit applications to the relevant authorities

for a determination of a degree of disability, as it will then be an officially recognized disorder. Given the dwindling number of affected individuals (currently known about around 200 in Germany), this will not cause a wave of complaints among caseworkers, but a basic understanding of the problems faced by those affected should nevertheless be developed.

Since the external body and the internal body image of those affected by BID do not match, parallels can be drawn to the identity disorder of transgender people, who, under the Transsexual Act, are entitled to an "amputation" of their breasts or penis – however, this does not create a disability [11].

In addition to the goal of identifying with a disabled body, social equality is also a priority for those affected by BID, and thus also the acquisition of a corresponding disability card.

In the course of research, various explanations for the development and maintenance of body integrity dysphoria have emerged. According to Thiel [5], the desire for amputation in those affected by BID increases during or after a stressful situation. When a stressful situation occurs, intensifying amputation fantasies occur, leading to a reduction in the unpleasant stress state. This could represent a coping strategy with which the person affected by BID experiences a short-term positive consequence.

In a groundbreaking study in 2020, Saetta and colleagues [12] examined the brain mechanisms of BID in 16 affected individuals who wanted to have their left healthy leg removed. The primary sensorimotor area of the leg to be removed and the core area of conscious representation of body size and shape were functionally less connected to the rest of the brain than in normal individuals. Furthermore, the left premotor cortex, which is reportedly involved in the multisensory integration of limb information, was atrophied. The more severe the brain atrophy, the stronger the desire for amputation and the more the individual pretended to be an amputee by using a wheelchair or crutches to compensate for the discrepancy between the desired and actual body. The basis of BID is therefore functional alterations in higher-order areas of body representation, which are presumably responsible for dissatisfaction with a "standard body configuration". Ultimately, this appears to be a neurological dysfunction that exists since birth and compels those affected to adapt their external body to the mentally predetermined internal body schema over the long term. This also corresponds to what those affected report. As a rule, they have the feeling that "something is wrong" with their body since childhood, they are fascinated by the sight of other disabled people (and not frightened like a normal child), and invent creative games in which they can pretend to be a disabled person.

This study presented here, investigated whether there is any experience, how many people have already been granted a disability certificate, and the extent to which a disability certificate impacts the mental state of those affected by a disability certificate.

Study

To determine the current status of the recognition of a GdB due to the presence of a Body Integrity Disorder, a survey of those affected was conducted. The sample of those affected included 48 participants. Of these, 40 were men (average age 47.0 years, 18-74 years) and 8 were women (average age 35.7 years, 18-59 years). Table 2 shows that the majority of those affected by BID have not yet applied for a disability assessment, as developed, for example, by Garbos., *et al*. [13]. However, 4 women and 9 men were granted a degree of disability.

Official degree of disability (scale 0-100)	Women (n = 8)	Men (n = 40)	All (n = 48)
no	4 (50%)	31 (75.6%)	35 (71.4%)
20	-	-	-
30	1 (12.5%)	1 (2.4%)	2 (4%)
40	-	-	-
50	1 (12.5%)	-	1 (2%)
60	1 (12.5%)	2 (4.8%)	3 (6%)
70	-	1 (2.4%)	1 (2%)
80	1 (12.5%)	2 (4.8%)	3 (6%)
90	-	2 (4.8%)	2 (4%)
100	-	1 (2.4%)	1 (2%)

Table 2: Number of participants affected by BID in this study with and without a degree of disability.

The data were compared with a group of patients (n = 35), who had received a disability rating (amputation or paralysis) due to a real physical impairment.

The results of a post-hoc test after statistical testing using an analysis of variance (ANOVA) showed that there were significant differences between those with BID and the control group, who had a recognized disability rating due to a physical impairment.

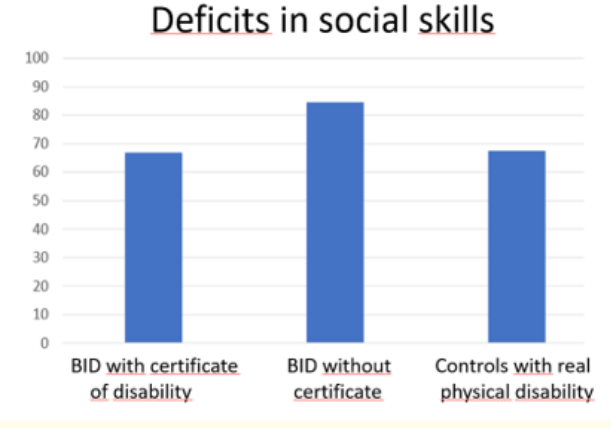

Figure 1: Extent of social skills deficits in the group of people with BID with a recognized degree of disability, without a degree of disability, and in the control group.

The graphic above shows that people with BID without a degree of disability are most likely to exhibit problems in the area of social skills deficits (see Figure 1). Social skills deficits are defined as those who, among other things, lack the necessary skills to successfully handle social situations. Many affected people therefore experience certain social situations as difficult or unpleasant. This often leads to avoidance of social situations and thus to a reduction in social contacts and activities [14-16]. This is understandable, as people with BID always run the risk of something happening when pretending (e.g., in a wheelchair), and then they have no proof of their disability. This leads to constant uncertainty.

Of the 48 subjects affected by Body Integrity Dysphoria, 34 reported having self-diagnosed the disorder. This means that only a small proportion have a solid medical diagnosis, which is due to the fact that there are hardly any specialists in Germany who can competently assess this.

Those affected by BID were asked in a further question to self-assess their BID severity. The question was answered using a Likert scale from 0 = "rather mild" to 5 = "very severe". The results showed that both genders rated their BID severity as "severe" on average.

However, of the BID subjects who had a recognized disability card (n = 13), only six subjects reported having obtained their disability card solely due to Body Integrity Dysphoria. Four subjects reported having obtained their disability card in conjunction with other diagnoses. Unfortunately, three subjects abstained from answering this important question. Regarding the question of whether those affected by Body Integrity Dysphoria had difficulties in obtaining a disability card, all stated that this was the case.

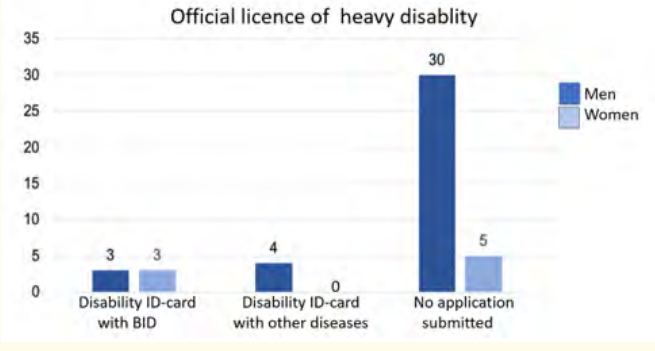

Figure 2: Number of people with BID who have received a disability certificate or have not yet applied for one (missing data n = 3).

One participant wrote that the state welfare office was unable to deal with the BID condition. Two of the participants answered the question that they had not yet received a medical diagnosis for their BID condition and therefore could not apply for one. Three of the respondents definitely did not want to have a disability certificate. One of the participants stated that he was embarrassed to go to the city hall and apply for a disability certificate because of BID.

As said above, for those with BID who permanently pretend to be disabled, for example, by using a wheelchair, this can lead to atrophy of the leg muscles. Of the 48 people with BID, 40 stated that their muscles have already atrophied.

Furthermore, the people with BID were asked what advantages they hope to gain from a disability certificate and why they generally want a disability certificate. Some statements should be quoted here:

"It feels right, as I see myself as physically disabled. I have a real handicap, although not one that restricts me too much".

Recognition in society. Recognition of the disability through BID, parking privileges due to wheelchair use".

"That BID is also recognized as a physical disability".

"No questions asked about reduced prices in museums, etc., no questions asked when booking train or flight travel. The ability to use appropriate parking spaces as a wheelchair user when there are no other adequate parking options".

"A parking permit for disabled parking spaces so I can unload my wheelchair from my car, applying for a toilet key, official recognition of my disability, even if I'm in a wheelchair 'voluntarily,' and being able to show the permit if necessary".

"If I ever seek a disability permit because of BID, it would only be to clearly demonstrate the extent to which I perceive myself to be limited".

"That it becomes a real disability and not, as many continue to believe, just a fetish they want to indulge in. You're usually met with hostility in forums or groups because you don't have a disability card and only want to have the disability for fun".

"The most important advantage for me was that I was only able to apply for a parking permit with my severely disabled person's permit, since I still drive and, due to my permanent wheelchair use, I already have to park in disabled parking spaces".

In the following open question, those affected were asked what problems they had experienced because they didn't have a disability card. Some of the answers were also verbatim:

"No external recognition of the disability. Difficulties with pretending, especially when parking: loading and unloading the vehicle".

"Currently, I only have a simple green Disability card without the G symbol and without the orange marking. Questions often arise as to why I don't have a disability card with the G symbol, even though I obviously have a significant walking disability".

"Explanations of why one has the disability".

The results indicate that the respondents pretend on average two to three times a week. However, they rarely pretend in public, possibly due to a lack of a disability card. Most use wheelchairs, orthesis or crutches (see Figure 3).

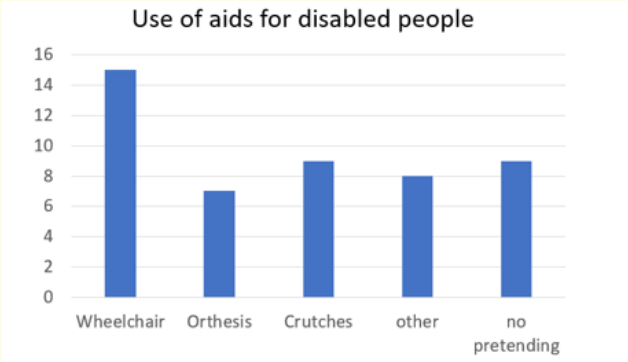

Figure 3: Frequency distribution of aids used to pretend by those affected by BID.

Discussion

The aim of this study was to investigate the extent to which the disability card impacts the mental psyche of those affected by Body Integrity Dysphoria. BID individuals without a state-approved

disability card primarily desire such a card because it gives them a sense of acceptance. They also want to avoid the exclusion they experience due to feigning a disability.

Furthermore, the results regarding social skills deficits showed a significant difference between the control group and the BID group with and without a recognized disability card. Social skills deficits are said to occur when a person lacks, among other things, the necessary skills to successfully handle social situations. In the study, those affected by BID without a recognized disability card achieved the highest scores for social skills deficits. One possible reason could be that they repeatedly have to explain why, for example, they are in a wheelchair, and therefore avoid social contact as much as possible. Compared to those affected by BID with a disability card, who achieved the lowest scores in this study, those affected by BID without a recognized degree of disability (GdB) have no proof, which ultimately provides them with a certain officially confirmed security. Those affected by BID without a degree of disability (GdB) are therefore increasingly exposed to insecurities. Since those affected by BID sometimes have to either conceal their illness from their partner or permanently simulate a disability, many BID sufferers prefer not to enter into intimate relationships at all. Once people with BID have a recognized disability card, it is assumed that they will have greater satisfaction within their relationship due to the recognition of their condition.

In summary, it can be said that a small group of people with BID already have a classification as disabled. Ultimately, while there is no physical indication here, there is a psychological one, which would equate this group with patients who have acquired a physical disability, for example, through an accident-related amputation or paraplegia. Due to the constant use of a wheelchair during pretending, the leg muscles of many affected individuals have atrophied to such an extent that they can no longer actually walk long distances with their legs. This is understandable given that no one has voluntarily acquired this disorder. According to current research, neurological damage to the brain has been present since birth, for which the affected individuals are in no way responsible. Just as in the case of accident-related paraplegia, for example, none of them voluntarily chose to be in a wheelchair. The difference appears to be that people with physically caused paralysis can no longer use their legs, whereas those affected by BID, at first glance, no longer "want" to. Current research contradicts this assumption. Ultimately, neurological damage forces both groups to lose the use of their legs. They are fully aware of the disadvantages of constantly sitting in a wheelchair.

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