

## Which Leg Shall I Cut Off?

### Body Integrity Dysphoria (BID) is not only a neurologic disease -Results of five case-studies

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**Summary:**Body Integrity Dysphoria (BID, formerly known as Body Integrity Identity Disorder, BIID) is the intensive feeling that the body will be "more complete" after the amputation of a limb. One explanation is a defect of the somatosensory cortex due to e.g. a developmental mistake in a fetal status with the result of a reduced representation of the concerned limb in the CNS. In this short article the data of five subjects are presented. Here, the need for an amputation has changed, e.g. from the left to the right leg. This finding is not in accordance with the theory of brain dysfunction. These people rather have the ideal to have a stump instead of an arm or a leg. Many of them see one-legged or one-armed persons as "heroes" who still survive in an awkward environment due to personal strength and in spite of their handicap. Suggested is a developmental theory in three phases: 1. eurobiological base: an "error" of body representation, achieved in a fetal status (genetic or due to a minimal brain lesion); 2. Developmental influence: Identification with a handicapped person in a sensible phase of early youth and 3. Confirmation: stress, frustration and sexual identity problems lead to lead to an unstable living situation. Through pretending with crutches or in a wheelchair, those affected experience relaxation and inner peace; this is repeated in other frustrating life situations and there is the stabilization of the idea that an amputation solves all problems.

**Keywords:** BID, Body Integrity Dysphoria, BIID, Body Integrity Identity Disorder, Apotemnophilia, Wannabe, Xenomelia

#### 1. Introduction

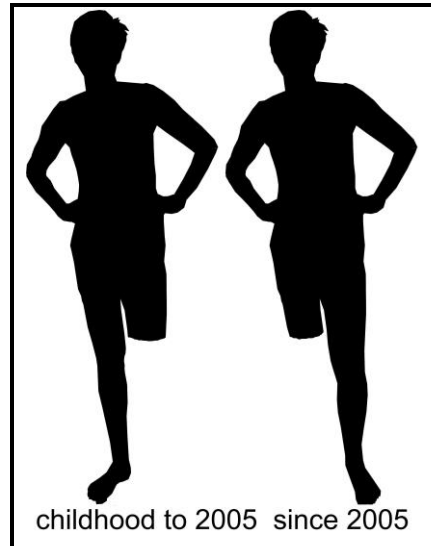
Mysteriously, some people have an intensive feeling their body will be "more complete" after the amputation of a limb. This phenomenon was named "Apotemnophilia" by Money et al.[5], "Body Integrity Identity Disorder" (BIID) by First [2] or the sufferers as "wannabes" (i.e. want-to-be amputees on the internet forums). The new versions of the DSM and ICD now called it "Body Integrity Dysphoria", comparing it with "Gender Dysphoria". The main motivation was to correct a mismatch between the person's actual anatomy and a sense of the mental representation of the body. On the other hand, one affected person argued to this description: "My body is complete, with legs, represented in my consciousness, there is nothing missing; I feel every hair on my legs.

*But I also feel that there should be two stumps (hidden in the thighs) and how they would be."*

One explanation of the desire is a developmental mistake of the central nerve system (CNS) in a fetal status or in early childhood, e.g. as a consequence of craniocerebral injury or of the sickness of the mother (Müller [6]). In this theory it is supposed that the somatosensory cortex for the limb in question has a dysfunction, i.e. a reduced representation of the concerned leg or arm in the CNS. The following five cases show this theory does not fit at least to all BIID subjects.

#### 2. Description of the cases

During our research about BID in the last years, several individuals got in touch with us. During an inquiry of some subjects, we found five cases where need for amputation had changed from one side of the body to the other.



**Fig. 1:** Subject No. 1 first wished an amputation of the left leg, in 2005 the location changed from the left to the right leg.

Subject No. 1 (male, 47 years old, university clerk, desire for amputation since an age of 8 or 9 years) first felt the need for an amputation of the left leg in the thigh about 20 to 25 cm above the knee. In 2005 the location changed from the left to the right leg. The reason was an inflammation of the right leg.

Subject No. 2 (male, 36 years old, freelancer, desire for amputation since about an age of 4 or 5 years): From his childhood until 2002 he wanted his left leg amputated; for unknown reasons the desire then was

focused for one year on the right leg and changed again 2003 to the left side. 2002 he had a disease and an arthroscopy in the left knee; the cause for the change was the consideration that it would be better to lose a defective leg.

Subject No. 3 (male, 32 years old, business administration, wish for amputation from 8 to 10 years of age) had a fracture of one of his legs at the age of 3 years (does not remember which of both legs). At an age between 8 and 10 years he developed the need for an amputation of both arms. Since an age of about 15 to 16 years the required amputation changed to the right leg. Beginning from 21 or 22 years of age he had the mysterious desire for a double amputation of the right leg and the right index finger.

Subject No. 4 (male, 72 years old, working in the entertainment sector, need for amputation since 12 years of age): At the age of about one year he suffered from poliomyelitis; at 50 years he had an accident with a fracture of the skull. In his youth he had felt the need for an amputation of his left leg. From about 1970 to 1980 the desire generalized on both legs and since 1980 it was again the left leg only (at all points of time exactly the same location in the middle of the thigh). Meanwhile, due to his age, he has abandoned his wish for an amputation, but began an erotic relationship with an amputee.

Subject No. 5 (male, about 41 years old, businessman, need for amputation since about 8 years of age). In his youth he had the idea of a stiffening of the lower part of the backbone, which later changed into the desire for palsy of both legs. As a young man he decided to “disable” the lower part of his body with a toxic injection into the spinal cord, but following the early death of his father he was asked to take over the company of his family and had to put this wish aside for several years.

As the main experiences for their desire for amputation, the subjects told:

Subject #1 wrote: *“Since my early childhood (8 or 9 years) I’ve felt fascination for amputated people: The mother of a friend of mine had lost an arm in World-War II, just like a physician who treated me. When I was about 10 years old, my haircutter told me that his colleague had had a motorcycle accident and lost a leg – I felt like electrified.”* [...] *“In December 2005 I saw in a newspaper the drawing of an athlete with a sporting prosthesis – again I felt like electrified. Since then the wish has been greater than ever before.”*

As a trigger for his wish subject #3 reported how he regularly watched a man with missing right arm in his town.

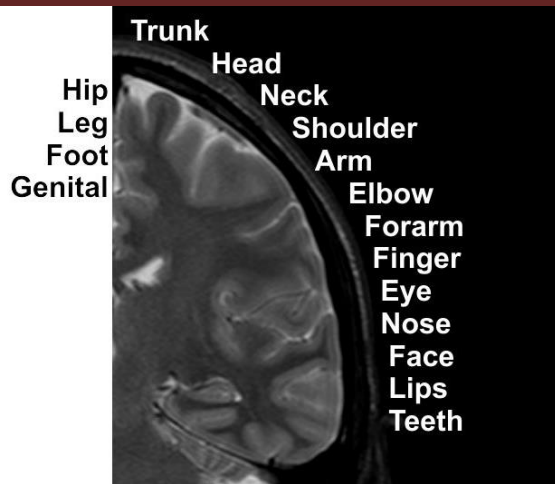
Subject #4 said: *“Shortly after World-War II, I was about 10 years old, when the Mall on Alexanderplatz in*

*Berlin was only a ruin, (...) I saw a boy in a cavity, not much older than I was; he was selling something there. He had an amputation of both legs from the thighs. Later, whenever I’ve passed this location, I always was hoping to see him again.”* [...] *“When I was 12 years old, I bent my knees and put them in a pair of sporting trousers, so that the feet were behind the buttocks. I jumped around, set two chairs to the left and to the right beside me, put my hands on them and pressed me so high, that the stumps hovered about the base, and tried to swing to and fro. This needs a lot of power. And just then, exactly during this trial of strength came the ‘feeling’, how I called it. Back then I never had heard anything about orgasm.”*

Subject #5 told me about the following e collection: *“In 1974 I was 8 years old. On a sunny summer afternoon in Cologne suddenly a young man in a wheelchair came in sight. Until today I feel drawn to him in an inexplicable way. In vain I tried to convince my father to follow this man. Inextinguishably the picture of this man was burnt into my memory; his thin legs, the back straight as a post, the balance of the upper parts of his body and the powerful arms. His upper body seemed to be shaped like a triangle with a short muscular upper part and the imagined arms of the angle ending in the lower part of his torso. The cubistic looking picture of this young man became an unpredictable ideal for my own body.”*

### 3. Discussion

At first glance, BIID has several parallels with neurologic disorders. In brain-damaged patients suffering from neglect or asomatognosia often a syndrome occurs that the subject has the feeling a limb does not belong to his or her body. E.g. Oliver Sacks [7] described a patient suffering from post-stroke neglect who tried to push his leg out of the bed because he was unable to accept it as part of his own body. Usually in these patients large destruction of the somatosensory cortex was found and the unrelated limb was paretic or palsied. As far as we know, a comparable lesion of the somatosensory cortex in BIID-people never has been found. Bayne and Levy [1] argued against this theory that “wannabes” do not exhibit any of the impairments in control of movement that one would expect in a person with distorted body schema. Further these authors said that most subjects with an amputation desire planned to use prostheses (or those who had an amputation already do so). If the limb was not represented in their brain, this would not be the case.



**Fig. 2:** Somatosensory areas of the parietal lobe. A traumatic injury is more likely on the outside than in the interhemispheric cleft of the brain. If a minimal lesion is the cause of BID, the arm should be affected more than the legs. In addition, there should be cases that the nose, mouth or other parts do not feel like part of their body.

In the study of First [2] 47 subjects wanted a specific limb amputated, 38 that of a leg and 7 of an arm. In my opinion, this finding is of high importance. If the desire for amputation results from a brain dysfunction achieved as a fetus or in early childhood, there should be nearly the same number of wishes for arm and leg amputation. The cerebral representation of the arm lies on the upper outer side of the brain, which during birth or in early childhood more easily can be damaged. In contrast, the areas of representation of the feet and lower parts of the legs are well protected in the gap between the hemispheres. If there would be a lesion due to traumatic damage there should be more BID cases with the need for an amputation of the arms and not of the legs. But it is just the other way round.

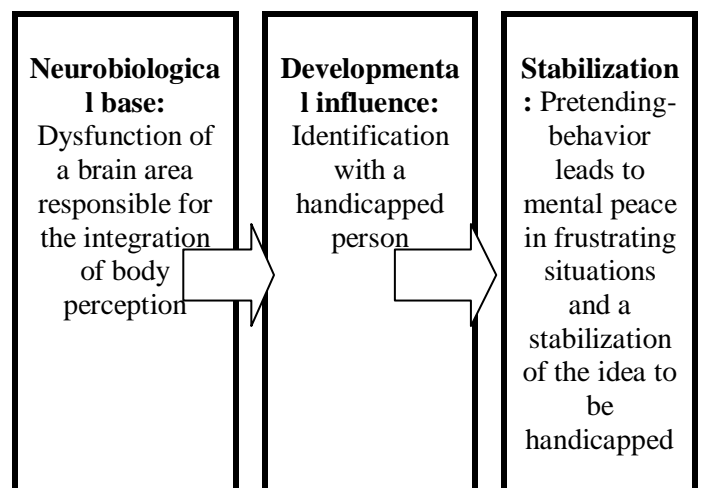
The change of the wish for amputation in the 5 subjects presented here shows that an isolated brain dysfunction theory of the somatosensory cortex is not appropriate. Interestingly there seem to be intellectually driven or influenced reasons where exactly the amputation should be made. For instance inflammation of the so far remaining limb has been reported to have led to such a change. Other authors described more of such cognitive-based changes. While the amputation of an arm leads to many problems in activities of daily livings, a missing leg does not have such negative restrictions; a wheelchair, artificial limb or crutches can compensate leg amputation. In the data of the First 44 of the 52 interrogated people specified laterality; only 12 wanted a right-sided amputation (which e.g. leads to problems in-car driving). Another 12 of the subjects in the study of First had variable patterns in regard to the localization of the amputation, some would have been

satisfied by amputation of any limb, and in others the preference changed over time.

These findings do not support the idea that only a CNS defect is responsible for BIID. Much more these people have an ideal to be handicapped. Many of them see one-legged or one-armed persons as “heroes” who still survive in an awkward environment due to personal strength and in spite of their handicap. Therefore it does not surprise that many individuals who got an amputation go on to accomplish feats such as skiing, mountain climbing, bicycle racing, and other activities that normally do not fit with the superficial picture of a one-legged person (Horn [3]). Sports like the “Paralympics” (e.g. Oscar Pistorius) show that the abilities of these “handicapped” people often were much better than in the average population.

A multi-causal developmental theory in three phases can be as follow:

1. Neurobiological base: Every cognition and behavior must have a neuropsychological base. Supposedly anything went wrong in an early phase of CNS development in a fetal stadium. Responsible for BIID is not a lesion of the somatosensory cortex, which will lead to somatosensory deficits as in patients with hemiplegia. More appropriate could be a dysfunction in the parietal lobe, in the parieto-temporal junction or in the thalamic area.



**Fig. 3:** Multi-causal model of BIID development in three phases.

2. Developmental influence: The brains of those affected are virtually prepared for it according to the lock and key principle and the children react differently. While normal children are frightened or sad when they see a disabled person, BIID-children find the sight fascinating and have the feeling: “*I want to be like that too*”. Identification with an amputated person in a sensible phase of childhood seems to have impressed most BIID subjects. Perhaps here, the

mental image seems to be that handicapped patients got more attention from their environment? Based on the neurobiological dysfunction, these experiences had much more influence on the further development than in other people.

3. Stabilization: In adult life stress, frustration and sexual identity problems lead to an unstable living situation. Through pretending with crutches or in a wheelchair, those affected experience relaxation and inner peace; this is repeated in other frustrating life situations and there is the stabilization of the idea that an amputation solves all problems. Here, there exist parallels with Body Dysmorphic Disorders as well as with Gender Identity Disorders.

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