

# Effects of psychotherapy on patients suffering from Body Integrity Identity Disorder (BIID)

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**Abstract:** People suffering from Body Integrity Identity Disorder (BIID) feel the intense desire for a physical disability (e.g. amputation or palsy of a limb). The suffering is caused by a divergence between their intact real body and their desired mental self-image of a disabled person. Aim of this pilot-study was to answer the question, whether psychotherapy can help to prevent the desire for amputation or palsy. Methods: A questionnaire was developed to investigate experiences with psychotherapy in BIID-patients. These people were asked about the success of different psychological and psychopharmacological types of therapy. Respondents stated whether they experienced an increase or decrease of their desire for amputation or palsy due to the specific kind of therapy and to what extent their psychological strain had been changed after therapy. Results: BIID is a very rare disturbance; still 25 people were investigated in this study. 32% had psychopharmacological treatment, 24% had cognitive behavioral therapy, 20% psychodynamic therapy, 20% had trained a relaxation technique, 8% had counseling therapy and 4% had experiences with art- and body-centered exercise therapies. In contrast to our hypothesis, all therapy-methods tended to cause an increase of the desire for obtaining a disability. A higher number of therapy sessions was positively correlated with an increased desire for an amputation, paralysis or other disability. On the other hand, the psychological strain in relation to BIID was reduced by all types of therapies; the highest reduction could be reached with psychodynamic therapy. Conclusion: Psychotherapy can reduce the psychological strain in BIID affected persons. The fact that the desire to obtain a disability increases during the therapy is explained as a result of an intense exchange about BIID with the therapist.

**Keywords:** Body Integrity Identity Disorder, Amputee Identity Disorder, Xenomelia, Body Incongruence Disorder, Psychotherapy, Amputation, Palsy

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## 1. Introduction

Body Integrity Identity Disorder (BIID, also termed as: Amputee Identity Disorder, Xenomelia, Body Incongruence Disorder) is a disease, where a person feels an intense desire to achieve and obtain a physical disability. The affected people have an intense feeling, that only with an amputation, palsy or other kinds of handicap; they can bring their intact body in congruence with the mental body scheme of a disabled person. In 2007 Mueller [10] argues against the fulfillment of the desire for amputation, because there always is a possibility that possibly in the future helpful therapeutic methods are found, but then the amputation cannot be made undone. In contrast, Bayne and Levy [1] uttered the opinion that the BIID afflicted persons are satisfied after an amputation and do not want any

further operations. A study by Noll [12] with 19 BIID sufferers who have been amputated successfully showed that most were free of symptoms even years after the operation and did not regret their decision. Based on these findings, currently the concerned people demand a legalization of such an operation. Their right for self-determination is seen as the strongest argument for such legalization [14].

Currently, it is difficult to come to a decision pro or contra surgery, because other treatment options for BIID-patients have not yet been studied adequately. At present, BIID is seen as an identity disorder, and several parallels exist to gender identity disorder, which is the most important other form of identity diseases. In both disturbances, the real appearance and the mental body scheme do not match. Both groups of patients feel like they are living in the wrong body since early childhood and

often surgery is seen as the only helpful form of treatment.

A common side effect of BIID is the existence of depression in about 20% [16]. Stirn, Thiel & Oddo developed the explanation that constant thinking about the problem of achieving an amputation leads to a depressive mood, because the sufferer is not able to find a solution for this problem. The authors found a slight, non-pathological obsession in about 80% of BIID sufferers. With 30 BIID participants, Stirn *et al.* [16] made clinical interviews, questionnaires, and functional imaging techniques. Their findings support the results already described by First [4], and Spithaler & Kasten [15]: Most of the BIID affected people show no severe psychopathological aberrations, they are intelligent, successful in their jobs, have autonomous personalities, and often show narcissistic and slightly obsessive characteristics.

The first evidence of a neurological origin was found by Brang, McGeoch and Ramachandran [3] in their study with two BIID patients. These authors suggested that in BIID as well as in Somatoparaphrenia a dysfunction of the right parietal lobe lead to a distorted body image. This result was underlined by the fact that BIID patients can draw a precise and generally stable line for the desired amputation [4]. Measurement of skin conductivity above and below the desired amputation line showed an increased skin conductance below the line, which, so the authors conclude, could suit to a congenital dysfunction of the right parietal superior lobe. In addition, McGeoch, Brang, Song, Lee, Huang & Ramachandran studied brain-activity in four BIID sufferers [8]. The participants were touched on both feet, and the results showed that no activation of the right superior parietal lobe was seen for the foot which the person wants to amputate. In the other foot a normal activation was found.

On the other hand, First [4] as well as Kasten & Stirn [7] described BIID sufferers with changes of their request for amputation from one side to another. The authors interpreted this as an indication that the wish for amputation is not only the result of neurological brain damage, but also strong psychological components for the origin of BIID.

Using functional magnetic resonance imaging, Oddo *et al.* [13] investigated 12 BIID sufferers and found that the desire for an amputation not only has an anchoring in the sensomotoric parts of the brain. Significant activations were found in areas of emotional and rewarding brain structures. These results argue against a purely neurological explanation for the origin of BIID. We need an integrated neurobiological and biosocial-psychological explanatory model.

Important for the here presented pilot-study is the essential hypothesis: When a psychotherapeutic intervention is helpful for BIID-patients, this underlines the psychosocial cause of the wish for amputation or palsy.

Until now, there are only few studies about the effects of psychotherapy in BIID patients; most were only single case reports. Braam *et al.* [2] published 2006 their results about the efficacy of psychotherapeutic and medical treatment for BIID in a single patient. Here, a cognitive behavioral therapy led to a weakening of the desire for amputation. The patient learned methods to reduce his suffering, but the desire did not vanish entirely. Thiel and co-authors [17] integrated psychodynamic and cognitive-behavioral elements. Their patients could reflect that the desire for amputation was strongest in situations of frustration, dissatisfaction and disappointment and rare in positive situations of his life. This insight helps the patient reduce his desire for BIID and makes him feel an emotional relief.

**Table 1.** Results of a questionnaire about the effects of psychotherapy in the BIID internet forum "fighting-it@yahoogroups.com" (2013).

Question	Percent of participants (number of votes)
No, I haven't tried therapy and I am not planning to do so	23.6% (30)
No, I haven't tried out therapy, but I would like to	6.3% (8)
Yes, I have done therapy	10.2% (13)
I was in therapy for up to 3 months	11.8% (15)
I was in therapy for more than 3 months and less than 2 years	1.6% (2)
I was in therapy for more than 2 years	2.4% (3)
Therapy included other methods or elements	2.4% (3)
Therapy has helped to reduce the urge	0.8% (1)
I know now what to do when BIID gets high	0.0% (0)
After therapy I know clearly and am decided to get surgery	3.9% (5)
After therapy I have decided against surgery	0.0% (0)
After therapy I am undecided	3.9% (5)
Therapy was good for me	3.2% (4)
Therapy has helped me to overcome BIID mostly (I'm now mostly free of the desire)	0.0% (0)
Therapy has helped to overcome problems that are effects of BIID (like guilt, shame, secret life, being unsecure, ...)	4.7% (6)
Therapy has not (or only for short times) helped to reduce the urge	9.5% (12)
Therapy was not good for me	5.5% (7)

Noll [12] investigated 19 BIID patients, who had successfully achieved an operation, about their personal success with the amputation. In addition they asked these patients, whether they had had a therapy before they

decided to have a surgery. Seven persons had never had any treatment. Six BIID-sufferers participated in psychoanalysis, seven in behavioral therapy; three had depth-psychology, twelve counseling, one psychodrama

and another participant had crossed the box for “other form of psychotherapy”. Only two persons said, that they had felt a profit from their form of therapy, all of them had had counseling therapy. In contrast the desire for amputation increased in five other cases during a therapy. Twelve persons had taken psychopharmacological medications. Ten got antidepressants, two neuroleptic drugs, another two tranquilizers and four tried other forms of medication to reduce the desire for amputation. These medications had no positive effects, about two thirds of these twelve patients stated that the desire for surgery was constant and in about one third the BIID-desire increased. Thirteen persons used relaxation techniques; several tried more than one method, one of them up to five different kinds of methods. Eight used autogenic training, seven used mediation and five progressive muscle relaxation. Yoga and QiGong were used by one person; two participants chose the category “others”. The majority of these persons did not profit from relaxation techniques. Due to the concentration on the body, the BIID desire increased in 53.9%, only 15% persons stated decreased wishes for amputation (one made autogenic training, the other progressive muscle relaxation). It is not possible to generalize these results, because this is a group who eventually decided for an operation and it must be assumed that they decided, because therapy had no benefit.

Another not exactly scientifically standardized study with 127 participants was made in the BIID internet-forum “fighting-it@yahooogroups.com”. The results of this questionnaire were published by the administrator of this homepage in October 2013 (see Tab.1).

The most important question of the here presented work is, whether therapies are helpful for BIID sufferers and, if so, to differentiate between the benefit of different psychotherapeutic methods.

## 2. Methods

### 2.1. Questionnaire

The questionnaire of the here presented study was developed with the program “SosciSurvey” to enable a computer-based data collection. According to new studies, computer-based methods show greater accuracy and better formal quality as opposed to non-computerized surveys (see e.g. Moosbrugger & Kelava, [9]). In the questionnaire the most common therapeutic interventions were explained in detail to the participants. The results were analyzed statistically with SPSS. In form of significance test, mostly a U-test was used, a nonparametric test for independent samples. The significance level was  $p < 0.05$ ; correlations were calculated, due to the small number of participants, with the Spearman’s R. At first, the data were checked for inconsistent answers. The reliability of the questionnaire was tested with comparison of the answers in pairs of similar items. Data were sorted out, when inconsistent answers or a low reliability coefficient (between similar

items) was found.

### 2.2. Socio-Demographic Data

After the analysis of the exclusion criteria, the here presented results are based on the data of 25 participants. Investigation of the socio-demographic information showed that 19 (76%) were male and 6 (24%) female. The BIID affected persons were between 21 and 61 years old (average 44 years). 76 % classified themselves as heterosexual, 12% homosexual and 12% bisexual. On average, participants had suffered from BIID for 28 years ( $SD = \pm 15.27$  y.).

On a scale from 0 (not at all) to 100 (very much) the participants were asked to what extent BIID affects their quality of life. On average, a value of  $82 \pm 17.6$  (SD) was found. Negative influence on life satisfaction due to the desire for amputation was  $83.0 \pm 16.7$  and extent of psychological burden due to BIID was  $70.0 \pm 25.7$ . Only one participant claimed to experience no negative mental influence due to BIID.

9 (36%) of the participants had psychotherapy or pharmacological treatment, 16 (64%) never had any therapy. Some doubted the effectiveness of therapies; two were interested, but had no adequate opportunity to get therapy. Some other participants did not want to talk to anyone about BIID. Three patients described fear to be classified as “crazy”. Two participants of the therapy-group named depression and feelings of inferiority as additional reasons for their search for a therapy. Another participant had had two kinds of therapies, but not because of BIID and therefore didn’t answer the specific questions.

7 (= 77.8%) of the therapy-group participated in an outpatient therapy and 2 (22.2 %) in a stationary therapy. The costs were paid by the common national health insurance system in 77.8% of participants, one (11.1%) had private health insurance and another (11.1 %) paid for the therapy himself.

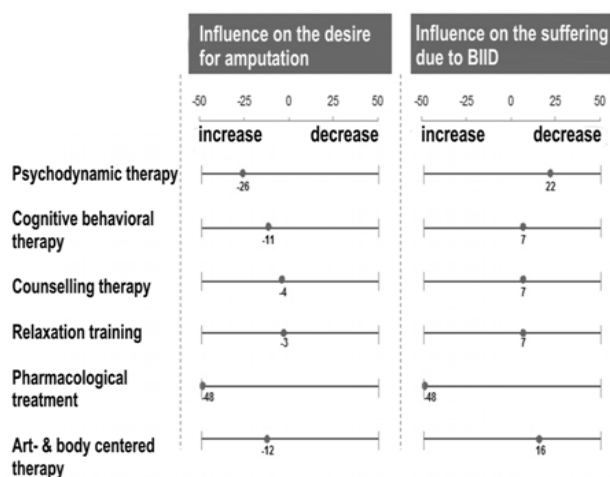
Asked whether psychotherapy harmed or helped, on a scale from -50 to +50, on average participants crossed  $9.0 \pm 22.9$  in the central area of the dimension, i.e. they had the opinion that psychotherapy neither is helpful nor harmful for their problems with BIID.

Out of the catalogue of the above described types of treatments in our participants only six therapies were used: the psychodynamic therapy, the cognitive behavioral method, counseling, relaxation techniques, pharmacological therapy and art- and movement therapy.

### 2.3. Psychodynamic Therapy

Five (55.5%) of BIID sufferers had done a psychodynamic therapy; one (11,1%) completed 1 therapy and 4 (44,4%) completed 2 of these therapies. In 44,4% a psychologist performed the treatment, in 11,1% a medical practitioner and in the remnant a physician/psychiatrist. The average number of therapy sessions was 49 (min. 10, max. 100 sessions). Two had ongoing therapy at the point

of the investigation, for one person, the treatment was finished one month ago and for the other two persons the therapies were finished between 2.5 und 3 years ago. 50 % of patients had therapy sessions more than once a week, 33.3% had weekly meetings and 16.7% had biweekly visits with their therapist. On a scale from -50 (= wish for BIID increased) to +50 (= decreased) the participants estimated the influence of the psychoanalytic therapy on their BIID-desire with an average value of  $-25.5 \pm 25.7$  i.e. due to the therapy the desire for an operation increased slightly. At the same time, the therapy reduced psychological strain on a scale from -50 (=suffering increased) to +50 (= suffering decreased) with an average value of  $21.5 \pm 24.6$ . The BIID sufferers were asked how they experienced the therapy sessions (scale from -50 = negative to +50 = positive). Here, the therapy session in the psychodynamic therapy was estimated as good (mean  $25.0 \pm 4.64$ ), i.e. due to the meetings, the persons made positive self-experiences.



**Figure 1.** Influence of six therapies on the desire for an amputation or palsy and influence on the suffering due to BIID.

#### 2.4. Behavioral Therapy

Six (66.6%) BIID sufferers have done a behavioral therapy (44,4% one and 22,2% had two therapies). In four cases a psychologist carried out the therapy and in the remnant a physician /psychiatrist performed it. All were individual therapies, i.e. no group therapy. On average, the length of therapy was  $28.5 \pm 22.7$  months. Two participants were in an ongoing therapy at the time of the survey, for two other patients the therapy was 2 years back and for another patient 15 months ago. Three (50%) of the patients had their therapy session weekly, two every two weeks and one had even fewer meetings. On the above explained scale from -50 to 50 the participants assessed the influence of the therapy on the desire for amputation with an average value of  $-11.0 \pm 20.8$ , i.e. the wish has slightly increased due to the therapy. In contrast, the therapy has slightly reduced the suffering with an average value of  $7.0 \pm 21.43$  on the same scale distribution.

#### 2.5. Counseling THERAPY

Only two (22.2%) BIID sufferers had experiences with a client-centered counseling psychotherapy; one with a psychologist, and another one with a psychiatrist. All have had individual therapy (i.e. no group sessions). On average, they underwent therapy for  $22.5 \pm 24.75$  months. In both patients the last therapy session was more than 2.5 years ago. One had weekly sessions and the other one had fewer meetings. On the scale from -50 to 50 the participants evaluated the influence of the therapy with an average of  $3.5 \pm 4.95$ , i.e. the therapy has the tendency of BIID neither reduced nor increased. On the other hand, the therapy reduced the psychological strain from the BIID desire slightly with an average value of  $7.0 \pm 21.21$  on the scale from -50 to +50. With this kind of psychotherapy the participants also made positive experiences ( $32.0 \pm 4.6$ ).

#### 2.6. Relaxation Techniques

Five participants (55.5%) learned a relaxation technique; some of them tried more than one of these methods. Four had done autogenic training, three exercised progressive muscle relaxation, one Shiatsu, and one used relaxation-music. One had learned the relaxation method with a psychologist, two with a medical practitioner, one had learned it autodidactic and two gave no answer. Four learned the method in a group and continued the training then independently at home. The intensity varied greatly: At the time of our investigation no one did the relaxation training regularly, two did the exercises irregularly (one of them for about 20 years), the remnant had carried out the exercises only for some weeks. On the scale from -50 to +50, the change of the BIID desire due to this method was  $-2.5 \pm 0.0$ , i.e. the therapy had no effect on the desire for BIID. However, on the other side, the relaxation trainings reduced the suffering very slightly ( $6.5 \pm 10.6$ ). In our study, relaxation techniques had not lead to a notable positive self-experience (mean  $9.0 \pm 10.8$ ). Interestingly, some persons stated to know their preferences in regard to BIID better after this form of therapy.

#### 2.7. Art- and Body-Centered Exercise Therapies

Only one participant (11.1%) had an art- and body-centered movement therapy with a psychologist. With weekly frequency he was in therapy for 1.5 months; the last meeting had been one week ago. The influence of this therapy on the desire for BIID was estimated as  $-12.0 \pm 0.0$ , i.e. a slight increase in the desire for BIID. With a value of  $16.0 \pm 0.0$  the suffering was slightly reduced due to the therapy. The therapy session was assessed as a slightly positive experience (mean  $10.6 \pm 0.0$ ).

#### 2.8. Psychopharmacological Treatment

8 (88.8%) of BIID sufferers had gotten a pharmacological treatment (5 patients got antidepressants, 3 antipsychotics). All forms of medication were prescribed from a physician, in

one case due to the advice of a psychologist. On average, they had taken the medication over a period of  $60 \pm 80.9$  months, at the point of the investigation no patient took such a medication; the last intake was between 2 weeks and 16 months ago. On the scale from -50 to +50 the influence of these medications on the desire for BIID was estimated with -48.0, i.e. the drugs were not helpful. Only one participant stated with a value of +44.0 that his suffering was reduced due to the medication.

### 2.9. Statistical Analysis

The Spearman's correlation coefficient between the number of therapy sessions and the decline of the desire for amputation was  $R = -0.13$  (n.s.), i.e. there is only an insignificant negative relation.

## 3. Discussion

BIID is a very rare disturbance and until now the effects of psychotherapy was described only in single case studies. We were able to investigate 25 BIID affected person, which is a large number in this field of research, but a small number for a reliable statistical analysis. Despite this small number of participants, we found several important results in this pilot study: Interestingly only 9 (36%) out of 25 BIID affected persons tried psychotherapy or a psychopharmacological medication to fight the desire for amputation. This is a highly critical point, because the BIID group on the one hand argues that they feel excessive suffering due to the difference between their mental state and the real body; on the other hand about two thirds of them never had looked for professional help. A possible explanation for this discrepancy may be that the strange desire for amputation is recognized as shameful and the sufferers were anxious to be labeled and stigmatized as "crazy lunatics" even from professionals. From a study by Neff & Kasten [11] it is known that several therapists had never heard anything about BIID and the disease often was misinterpreted.

On the other hand the BIID afflicted people show no psychopathological disturbances [4, 5, 6, 15, 16, 17]; they do not suffer from symptoms of a mental illness, but from the feeling of an supernumerary limb. The lack of such a disturbance makes it understandable that they rarely consult a psychotherapist.

It is important to notice that all forms of therapy increased the desire for BIID, strongest in the pharmacological treatment, weakest relaxation techniques. On the other hand the suffering was reduced due to all psychological therapies. A significant reduction of emotional pressure was reached due to the psychodynamic therapy, followed by the art and movement therapy and a slight reduction was achieved with cognitive behavioral therapy, counseling and relaxation techniques.

These findings underline the treatment study published in 2006 by Braam et al. [2] in their single case study. Here, cognitive behavioral therapy reduced the suffering, but the

desire for amputation still remained. As said in the introductory chapter of this article, Thiel et al. [17] described success of a long-term therapy by using psychodynamic as well as cognitive-behavioral elements.

Our study demonstrates that the wish to perform the operation increased during psychotherapeutic intervention. Our theory for the explanation of this unexpected result is that excessive talking about BIID in therapeutic sessions may have focused on the wish for amputation and increased the mental readiness to think about this problem. From personal communication with BIID affected persons and from the above cited study of Thiel and co-authors it is known that distraction often leads to a decrease of the wish for amputation while frustration and constant rumination about BIID leads to an increase. Even without treatment, the victims often spend a lot of time pondering whether and how they can achieve the disability and when they may dare to take this step. In therapy, the difference between the intact and the mental body will be one of the main themes, but the therapy can't solve this disunion. Perhaps talks about the desire in the therapeutic setting can be a stimulus, which may strengthen the endless loop of thinking about ways to achieve the disability.

On the other hand most patients learned how to cope with their desire and were provided with methods what they can do in daily life to push the wish for amputation aside in their therapy. This may have led to a reduction of the suffering.

Our study has several limitations. One bias may result from the fact that participants were found via a BIID internet page. Perhaps, persons who were cured after a therapy and lost their wish for amputation could not have been found by this way of recruiting. But, following all we know from personal talks with BIID affected persons as well as from literature and from postings in internet forums, no known case of a clear healing from the desire for amputation exists until now. Therefore we don't think that our way of recruiting participants has led to a systematic failure.

Another limitation is that our investigation was not a longitudinal analysis; the effects of therapeutic interventions were asked retrospectively only. A third limitation of our study is the fact that there was no standardized therapy. Every patient has had another therapist with different kinds of methods. None of the forms of therapy were developed specifically for the purpose of BIID affected subjects.

Therefore, the results of our study must be seen as preliminary. What we need now is a standardized longitudinal therapy-project with determined methods, which focuses on the specific needs of BIID patients.

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