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Voluntary amputation of a healthy limb - what do affected patients expect from the operation?

Abstract

There are people who suffer from the desire to have a leg or arm amputated. Only after removing of a limb the external body corresponds to their mental body image. Previous psychotherapeutic or psychopharmacological therapies have not been able to cure this condition.

Objective: This study investigated what those affected hope for or fear if they could achieve a surgical amputation, i.e., whether fulfilling their wish would reduce their suffering and what limitations these patients expect in their daily activities.

Method: Using a self-constructed questionnaire, we asked how the patients imagined life after an amputation (career, leisure time, sex life & partnership, and social contacts). The affected people were asked to evaluate their current condition and imagine themselves in the situation after an amputation. In addition, the results of the experimental group were compared with those of a control group that did not suffer from the desire for an amputation.

Sample: In the experimental group, n=45 (36 men and 9 women) completed the questionnaire. The average age was 46 years. A control group of the same size was used, and statistical twins were created who were matched in terms of age, gender, and where possible, sexual orientation.

Results: It was found that those affected had significantly worse scores in the categories of job, social contacts, sexuality, and relationships before surgery compared to the control group. When comparing the scores before and after imagined surgery in the experimental group, significantly higher scores were found in all categories except for leisure time after an (imagined) amputation.

Conclusion: People who are motivated by the need for an amputation expect the surgical removal of a body part to significantly improve their lives, but compared to the controls, they rarely see the disadvantages in everyday life.

Keywords: Body integrity dysphoria; Body integrity identity disorder; Xenomelia; Amputee identity disorder.

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Introduction

For most people, the idea of losing a body part through amputation is extremely frightening. For example, there are motorcyclists who have lost an arm in an accident, or smokers who had a leg amputated. The life of a disabled person is usually imagined as helpless and dependent on others; many patients subsequently fall into depression because their daily activities are severely limited. It is mysterious and, at first glance, completely incomprehensible that there are also people who wish to have an amputation. However, the term "wish" is not correct here; you wish something for birthday; what these patients want lies on a completely different level. Those affected do not have a "wish" for amputation, but rather a deep inner need to change their body. They only feel complete when (for example) a leg has been amputated. Having two legs feels wrong on a mental body level in the brain. The external body only corresponds to the body image when one leg ends in a stump.

The fact that there are people who feel the need for an amputation is nothing new. Money and co-authors [18] described the desire as "Apotemnophilia" as early as 1977 and saw a strong sexual component within it. The most well-known term was coined by the American psychiatrist First in 2005 [8] as "Body Integrity Identity Disorder" (BIID). Other, lesser-known terms include "Amputee Identity Disorder" [9] and "Xenomelia" [17]. The disorder has been included in the 11th edition of the International Classification of Mental Disorders (ICD-11) since 2022 and was renamed "Body Integrity Dysphoria (BID)".

Those affected by Body Integrity Dysphoria (BID) have a desire to change their body. They feel that a certain part of their body or sensory functions do not belong to them [1,4,23,24]. In most cases, this altered body image existed since childhood or early adolescence. The need to retain the desired disability becomes stronger over the course of life. In most cases, this involves the amputation of a limb, often the leg, rarely a hand [29]. For this reason, we will mostly refer to amputation in the following article. However, there are also cases in which those affected wish to be paraplegic or blind or deaf. Through the desired operation, they feel they will regain their full physical identity. Most are afraid to speak about their need because they believe they will be rejected. This is why family and relatives usually do not know about it and it is kept strictly secret. Many affected people lead a double life, which increases the suffering enormously. To get one step closer to fulfilling their need, many people begin to pretend. This means, for example, if they want to have a leg amputated, they bind the leg upwards and use crutches or sit in a wheelchair. Many do this only at home or travel to cities where they are largely unknown so that they can perform the pretending in peace.

Most people with BID remembered they have seen a physically disabled person in their early childhood and were fascinated by it. Those affected can often recall more encounters with physically disabled people in their childhood than those without BID. These experiences trigger early conflicts with their own body image [21]. Even as children, they often begin to incorporate a specific disability into their games. The initial fascination eventually turns into the desire to be amputated themselves. From this point on, the urge becomes increasingly urgent. Those affected spend a lot of time thinking about this topic; it severely impacts their everyday lives, and the suffering becomes very intense, as our society does not offer the possibility of having a healthy body part amputated legally in a clinic. For some affected people, the condition is so unbearable that they injure themselves so severely (e.g., gunshot wound to the leg, frostbite from dry ice) that an amputation must be performed by doctors.

The initial idea that someone who wanted to get rid of a healthy leg must be "lunatic and totally crazy" has not been scientifically proven [13,22]. Those affected are not psychotic and do not have impaired emotional processing [5]. They do not suffer from delusions [8,11-13]. However, the disorder is often unknown among specialists and patients are misdiagnosed [19].

Only depression is comorbid with BID, which could be explained by the high level of suffering [28]. Furthermore, increased obsessive-compulsive behaviour has been observed in many affected individuals. This can be explained by the constant preoccupation with the idea of an essentially impossible amputation [30].

In 2008, Brang, McGeoch, & Ramachandran classified BID as a neurological disorder [7]. They assume that certain parts of the brain show a malfunction, resulting in a lack of identification with a body part [27]. However, there are many characteristics of this disorder that cannot be explained solely neurologically. In some patients, the desire to amputate their right leg changes, for example, to amputate their left leg [14], which is difficult to explain by neurological malfunction alone.

What do those affected say?

Here are some brief quotes from authentic texts from those affected:

Case #1

Case #1 wrote that he is 34 years old and that since his early youth he has been driven by the desire to have an amputation below his right thigh. The last few years were characterized by accepting this need as part of himself. Nevertheless, he suffers from recurring and increasingly severe waves of the need to be one-legged. Several years ago he had tried through behavioural therapy to control these thoughts.

In another email, Case #1 wrote that he was well aware of the implicit and explicit consequences, but that for some time now, he had reached a point where, despite his acceptance of the urge for amputation, he could no longer move forward.

In a questionnaire, Case #1 wrote that he feels a need to have his right leg amputated from the thigh down, to correspond to his inner body image. The dissonance was leading to inner conflicts. He doesn't see any external event as the cause; the need to not have a right leg seems to have always been there. He seeks a life as a one-legged, disabled man**.**

Case #1 cites arguments in favour of amputation: "No more circling thoughts; body image matches reality; time for research can be used differently; headspace created by BID thoughts is freed up for other things."

Cons cited by him include: "Physical disability; limitations in everyday life; needing assistance; subsequent costs; discrimination due to ableism; and possible pain."

Case #2

Regarding to BID, he felt something was not right for as long as he can remember. It started to become clearer to him when he was about 9 years of age. He remembers distinctly meeting someone describing a transgender relative as a "woman

trapped in a man's body" and he felt that he identified in the same way, but in younger age it was not clear to him how. As he grew older, he started to talk to the body modification community. Some members of that community had BID and they introduced him to other people who had the same condition. As a good summary, he wrote: "As a child, I did not understand what the feeling was, but I felt something. As an adolescent, I understood that feeling was with my body. As an adult, I understood the exact locations." In case of an amputation, he plans to use crutches, but will try to minimize their use. He has no specific idea how his family will respond, if he really performs an amputation, but is afraid that they react very negative.

For the question "Do you have any explanation for the need for amputation? Case#2 wrote: "I don't really know. My life just feels very incomplete without it. I feel like I am always hiding something and I feel like everyone I meet has met a fake version of me."

Case#2 was asked about the pros and cons of an amputation. As Pro-arguments he wrote: "Get to move on with life; friendship / relationships feel difficult because I feel they are dealing with a fake version of me. I don't have many friends or a romantic partner. All my attempted relationships fall apart because I feel like I cannot be honest with them. Get rid of weird feelings in limbs. Stop spending time on imagining myself in my preferred body."

Contra-arguments were: "Adapting to disability. Financial cost of prosthetics. Time away from work for rehabilitation. I live a very inaccessible house so I would need to move. Difficult to return to my hobbies. Stigma attached to disability. Family disapproval. Difficult to find partner who would accept a disability."

Case #3

Case#3 wrote that he finds it very difficult to talk about his problem because he feels his desire is unnatural. Since childhood, he wanted to have his left leg amputated at the thigh. He wrote that in his youth he did not know why he had this wish. The need for amputation was always there in the background, sometimes more, sometimes less. There were times when he was able to suppress this wish more, but the topic never completely let go of him. Case#3 wrote that he felt like he was in two worlds. In one, he had to function and had to overcome great challenges in his job, on the other hand, he could not find peace because this leg would not leave him alone. He only felt well-being and calmer when he pretended to be one-legged, i.e. when he imitated the disability. He feels that it has gotten worse in recent years and he wrote that not a day goes by without this wish.

The pro-arguments that Case#3 cites in favour of amputation are: "More quality of life, a spirit of adventure, joy, inner peace, balance, no longer having to hide BID, no more secrecy, finally being able to be who I am, no more double life." The con-arguments are: "Risk of amputation surgery, risk of not being able to get a prosthesis, possibly a wheelchair in old age, restrictions on mobility, problems with the stump, some hobbies only possible to a limited extent or not at all."

Case #4

Case#4 wrote: "I remember that a classmate of mine broke his leg. He was in a cast and I felt ashamed to look at him or talk to him. The same thing happened later with other friends who were in a cast or with disabled kids. I remember in particular that I had a friend who had leg braces that excited me a lot. I went to visit him and touched them secretly. Later I have always been attracted to disabled people and I pretended to be one.

I remember that -before the internet- I imagined I was disabled to get excited, this happened in adolescence. I have always oscillated between attraction to disabled people and being disabled myself. Over time, however, I understood that the attraction left me unsatisfied and the real desire I had was to be disabled myself. In particular, my desire is to be an amputee and have a prosthesis, a fake leg with which I can walk. Something that others notice. I believe that there has been an development over time and today I only want to be an amputated man. I love aids for disabled people and especially crutches and prostheses.

Today I don't see any limits or problems in being an amputee, nothing scares me except the impact on my parents and on 2 or 3 people who are close to me. I believe that it is something that I can manage and in any case the discomfort that this creates for me is certainly less than the desire to be an amputated. I don't see any limits in my being an amputee, in fact I only see a lot of happiness: if I think about not having a leg, I feel serene and happy. Now instead I feel uncomfortable. I don't think I hate my leg, but I hate my situation as a non-disabled person. I really don't think I'll be unhappy as a disabled person. I would like to be amputated above the knee so that I can wear a prosthesis that I think I would wear a lot."

When asked about arguments for or against a disability, Case#4 only wrote in favor of the arguments: "My happiness." For him, the arguments against are: "Just the impact on my parents and friends, but I think it would pass after a short time."

Case #5

Case#5 wrote that he has been living with Body Integrity Dysphoria (BID) for 40 years now and that the level of suffering has become ever greater. He feels the urge to have his right leg amputated below the knee. There were phases when the desire to finally be the way he feels "right" was unbearable, he has now reached a phase in his life where he finally wants to be "complete". He wrote that his right lower leg does not belong to him and has been disturbing his body image for decades. Case#5 imitates the condition on one leg, but this only gives his head a short rest. Whenever he looks down at himself, he sees what doesn't actually belong there.

In a questionnaire, when asked what problems he was seeking professional help for, Case#5 wrote that he suffers from BID, i.e. specifically a desire to have his right lower leg amputated. The symptoms have existed for almost 40 years, and he feels that his right foot does not belong to his body. This problem affects his life and his thoughts mostly revolve around this topic: How he can finally be happy and achieve a state of inner peace.

He reports that when he was about ten years old, he saw an amputee woman on the way home from school and that was when something "clicked" inside him. He was fascinated and since then he has not been able to get the idea of wanting to be like that out of his head. When asked what he has done about it so far, Case#5 wrote that he has done breathing techniques, QiGong and relaxation exercises to calm these thoughts, and also does a lot of sport. He tried to have pleasant experiences in order to fill his head with positive thoughts.

Case#5 cites the following pro-arguments in favour of amputation: "Peace of mind, satisfaction with the inner body image, simply being happy, no longer feeling sadness and inner restlessness, no more lies."

The only contra-arguments mentioned are: "No longer being able to shower long while standing."

Explanatory approaches

There is still no real explanation for why someone would consider having a body part amputated. The cognitive-behavioral therapy approach [30] includes a neurobiological predisposition as the first factor. The second factor is the child's learning experience. Almost all affected individuals experience a pivotal moment in early childhood in which they meet an amputee, evaluate the situation extremely positively, and therefore remember the encounter fondly. Due to the neurobiological predisposition, the appearance of amputees is stored as "correct", and this leads to positive reinforcement. The third factor is parental upbringing. The child sees how much attention an amputee receives, identifies with this, and seeks out situations in which they can receive the security and affirmation they crave. Often, simply imagining themselves as an amputee is enough to trigger these positive feelings. Because they frequently have amputation fantasies, and each time they experience a sense of psychological well-being, the desire for an amputation is reinforced. Simulating the disability leads to pleasure and relaxation. The final factor is stress processing. This creates a conditioning effect: in stressful situations, fantasies of being disabled always arise in order to reduce stress. According to the authors, this leads to a long-term reinforcement of amputation fantasies.

This pivotal childhood experience could indicate a particular neural predisposition, as those affected react to an amputee with extremely positive feelings. Children without BID, on the other hand, tend to react with negative feelings. McGeoch et al. [17] explain BID as being caused by neural dysfunction in the right superior parietal lobe. The superior parietal lobe contributes to the formation of body image. Due to this dysfunction, the affected limb is not correctly represented in the body schema. The affected person then perceives this body part as superfluous, and the desire for amputation arises. Similar neurological disorders include hemineglect, alien limb syndrome, and somatophrenia. Because those affected by BID can state exactly where they would like their amputation to begin, and for most of them this is the left leg, the authors believe there must be a disorder of the right superior parietal lobe.

In another study [28], 11 participants were examined using fMRI. The aim was to determine whether neural differences arise when viewing images of the desired amputated body and the intact body. When viewing the intact body, the test group showed lower activity than when viewing the amputated body. In the BID group, the limbic system and areas responsible for feelings of reward and euphoria were activated when viewing their own amputated body. Overall, emotional processing was strongly involved.

In 2020 Saetta and co-authors [25] examined 16 patients who feel the need for a removal of the left healthy leg. 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 owner-ship. They help to understand the experience of body and self as a seamless unity.

In another study, Gandola et al. [10] used fMRI to evaluate whether these findings could be replicated. These authors measured brain activations during somatosensory stimulation and motor tasks in 10 BID-patients with a need for the amputation of the left leg and 14 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 the activation of somatosensory areas bilaterally. The authors conclude that BID is associated with the altered integration of somatosensory and motor signals in brain regions where the first integration of body-related signals is achieved through convergence.

In 2022 Saetta et al. [26] published another study in 16 men with BID with a long-lasting need for left leg amputation. 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 was less connected 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 may consolidate the current understanding of the neural correlates of the amputation variant of BID.

The neurological explanatory model is now widely accepted, but it does not explain why predominantly only limbs are affected and not, for example, the nose, ears or any other body part.

Studies on treatment options

To date, there are very few studies on treatment. Kröger, Schnell, and Kasten [15] surveyed participants' experiences with various therapies. Of the participants, 32% had undergone psychopharmacological treatment, 24% had undergone cognitive-behavioral therapy, 20% had undergone psychodynamic therapy, 20% had attempted relaxation techniques, and 4% had tried art or body therapies. The results show that the desire for amputation increases with the therapy, likely due to the intense preoccupation with the topic of BID. The more therapy sessions the participant attended, the greater the increase in the need for amputation. However, the symptoms and suffering could be alleviated by all forms of therapy. The greatest relief was achieved with psychodynamic therapies.

In their therapy study, Braam et al. [6] specifically examined the effects of cognitive behavioural therapy and antidepressants on one patient. SSRIs led to a reduction in stress-related discomfort, such as inner restlessness. However, the antidepressants did not reduce the desire for surgery. Cognitive behavioural therapy reduced the frequency of pretending, weakened the desire for surgery, and led to the learning of new behavioural patterns that reduced the distress.

Successful amputees

One of the first publications about successful amputees was the study by Berger, Lehrmann, Larson, Alverno, and Tsao [3]. The article described the fate of a fifty-year-old transsexual man. At around the age of 10, he began to admire physical disabilities and developed a desire to have both legs amputated. He achieved this after placing his legs in dry ice for seven hours. After the amputation, he experienced no remorse and stated that he felt very happy and now complete.

In the study by Noll and Kasten [20], 21 patients with BID who had already been amputated were interviewed using a questionnaire. This included questions about quality of life, social integration, changes in dreams, desire for further surgery, phantom pain, and mental status before and after the adaptation of the external body to the mental body image. The results show that none of the 21 respondents regretted this path. They felt more comfortable in their bodies and "complete" afterward. Furthermore, it was found that there was improvement in all areas of life examined. While there were difficulties coping with everyday life, these seemed nothing compared to the happiness and contentment they felt after the decision. Most respondents did not want to undergo further procedures. Many respondents reported that they were able to engage with other people better since the operation, and one person stated that they were more interested in their own family again.

In the study by First [8], limitations in social contacts, including relationships, were observed before the surgery, as relationships would limit those affected, for example, in pretending. Constantly thinking and pondering what life might be like after the surgery makes it difficult for them to concentrate on their work or leisure activities such as reading. Since there are so far few studies with people who have undergone surgery and it is very difficult to find BID patients who have undergone surgery, it cannot yet be said that all those affected feel better after the surgery.

Study on the expectations of those affected

In addition to the above-mentioned reports from BID sufferers, we conducted a study to capture expectations. The project was conducted at the Medical School Hamburg (MSH) in Germany. The study tested the hypotheses of whether BID sufferers believe they will be better or worse able to perform their jobs after an amputation, whether their relationships and sex life will change, and whether social contacts and leisure activities will change as a result of the amputation. Furthermore, the data from the BID group were compared with the assumptions of a control group that has no ambitions to have a body part amputated.

To determine this, a questionnaire was developed and data was collected using the Soscisurvey program. The final group consisted of 45 participants. None had previously undergone surgery. In the experimental group, 36 men and 9 women completed the questionnaire. The average age was 46 years. The youngest participant was 21 years old, and the oldest was 79 years old. 33 participants (73.3%) were heterosexual, 8(17.8%) were homosexual, and 4(8.9%) were bisexual. 35 participants (77.8%) reported having a high school diploma or a university of applied sciences entrance qualification. 10(22.2%) had a primary or secondary school diploma. 14(31.1%) participants were married at the time of the survey, 25(55.6%) reported being single, and 6(13.3%) were divorced. 28(84.4%) individuals pretended and 7(15.6%) did not.

For the control group, statistical twins were created, who were matched for age, gender, and, where possible, sexual orientation.

Results

The survey data on whether BID patients believe they are still able to work after an amputation showed a significant increase in all areas. A significant difference was found for the items on work ability ($M_{before\ surgery}$ = 8.09±2.53, $M_{after\ surgery}$ = 9.3±1.62, p<0.01), job satisfaction ($M_{before\ surgery}$ = 7.33±2.73, $M_{after\ surgery}$ = 9.24±2.07, p<0.01), ability to concentrate ($M_{before\ surgery}$ = 6.91±2.51, $M_{after\ surgery}$ = 9.80±1.27, p<0.01), and the ability to perform their job ($M_{before\ surgery}$ = 8.5±2.17, $M_{after\ surgery}$ = 9.41±1.97, p<0.05). The mean values after surgery were higher for all outcomes.

To compare the relationships, two items were examined. One was how committed the person was to their partner ($M_{before\ surgery}$ = 7.82±2.91, $M_{after\ surgery}$ = 9.03±2.78) and the other was the happiness in the relationship ($M_{before\ surgery}$ = 8.0±3.12, $M_{after\ surgery}$ = 8.53±3.37). Sex life was assessed using specific questions about this topic ($M_{before\ surgery}$ = 6.85±2.94, $M_{after\ surgery}$ = 8.66±2.59). Highly significant differences were found between the mean values before and after surgery for satisfaction with sex life and how committed the person was to their partner (p<0.01). A significant difference was found for happiness (p<0.05). The mean values after surgery were higher in all t-tests.

In regard to relationships with friends and acquaintances, a significant difference was found before and after the imagined surgery ($M_{pre\text{-}OP}$ = 8.8±2.10, $M_{post\text{-}OP}$ = 9.15±1.89, p<0.05). Highly significant differences (p<0.01) were found for social skills ($M_{before\ surgery}$ = 8.95±1.81, $M_{after\ surgery}$ = 9.30±1.87), for the question of how communicative the participants rated themselves ($M_{before\ surgery}$ = 8.02±2.40, $M_{after\ surgery}$ = 8.58±2.27), for the item loneliness ($M_{before\ surgery}$ = 7.47±3.14, $M_{after\ surgery}$ = 8.26±2.95), and for the fun factor the participants have with their friends ($M_{before\ surgery}$ = 8.19±2.00, $M_{after\ surgery}$ = 8.88±2.18). For the items "How much do you enjoy being around people now?" and "How much would you like to be around people after surgery?" Highly significant differences were found for the postoperative period ($M_{pre\text{-}OP}$ = 8.0±2.14, $M_{post\text{-}OP}$ = 8.77±2.20, p<0.01) and also for the question of how well the subjects can engage with their friends and acquaintances ($M_{pre\text{-}OP}$ = 8.21±2.02, $M_{post\text{-}OP}$ = 9.40±1.62, p<0.01). No significant difference was found for the item "acceptance among friends" ($M_{pre\text{-}OP}$ = 9.07±1.99, $M_{post\text{-}OP}$ = 9.05±2.18). For all significant results, the mean values for the questions were higher after the surgery.

To test the hypotheses regarding leisure activities, items relating to leisure activities, travel, and sports were tested. The mean values of the items in the experimental group before and after imagined surgery were compared. The t-test for the variables "leisure activities" revealed no significant difference ($M_{before\ surgery}$ = 8.82±2.17, $M_{after\ surgery}$ = 8.77±2.21). Travel was tested using questions regarding the physical ability to travel ($M_{before\ surgery}$ = 10.27±1.01, $M_{after\ surgery}$ = 9.38±1.95) and how much the subject would like to travel ($M_{before\ surgery}$ = 9.2±2.45, $M_{after\ surgery}$ = 9.27±2.44). There was a highly significant difference (p<0.01) in the questions regarding physical ability. The mean value before surgery was higher. No significant difference was found for the item regarding how much the subject would like to travel. The same was true for the questions about whether the subjects

could exercise before and after surgery ($M_{pre\text{-}surgery}$ = 8.63±2.27, $M_{post\text{-}surgery}$ = 8.28±2.40). There were almost no significant differences here.

A comparison of the means of the experimental group with those of the control group before surgery showed that BID patients were less satisfied than the control group in almost all areas.

When comparing the means between the experimental and control groups, a highly significant difference was found for most scales on the work before surgery scale ($M_{Exp.beforeSurgery}$ = 7.54±2.24, $M_{Control.beforeSurgery}$ = 8.93±2.40, p<0.01).

A highly significant difference was found between the experimental and control groups on the work before surgery scale ($M_{Exp.beforeSurgery}$ = 7.54±2.24, $M_{Control.beforeSurgery}$ = 8.93±2.40, p<0.01). The work-related items included work ability ($M_{Exp.\ pre\text{-}surgery}$ = 8.07±2.51, $M_{Control\ pre\text{-}surgery}$ = 9.42±2.43), job satisfaction ($M_{Exp.\ pre\text{-}surgery}$ = 7.33±2.73, $M_{Control\ pre\text{-}surgery}$ = 8.13±2.62), and how well the subjects could perform their jobs ($M_{Exp.\ pre\text{-}surgery}$ = 8.50±2.17, $M_{Control\ pre\text{-}surgery}$ = 9.31±3.03). There was a highly significant difference in work ability between the pre-surgery group (p<0.01). The mean values of the control group were higher.

The mean comparison of the sex life and relationship scale before surgery between the experimental and control groups revealed a highly significant difference ($M_{Exp\ pre\text{-}surgery}$ = 6.79±2.90, $M_{Control\ pre\text{-}surgery}$ = 8.21±2.64, p<0.01). In the relationship area, no significant differences were found for the item "happiness in the relationship" ($M_{Exp\ pre\text{-}surgery}$ = 8.00±3.12, $M_{Control\ pre\text{-}surgery}$ = 8.69±2.60) and the item "being able to commit to one's partner" ($M_{Exp\ pre\text{-}surgery}$ = 7.72±2.94, $M_{Control\ pre\text{-}surgery}$ = 8.42±3.08). A highly significant difference was found regarding the participants' perceptions of their current sex life ($M_{Exp.\ pre\text{-}surgery}$ = 6.32±2.84, $M_{Control.\ pre\text{-}surgery}$ = 7.82±3.00, p<0.01) and a significant difference was found regarding satisfaction with their sex life ($M_{Exp.\ pre\text{-}surgery}$ = 6.71±3.04, $M_{Control.\ pre\text{-}surgery}$ = 7.91±2.75, p<0.05). The mean score of the control group was always higher.

A highly significant difference was found between the experimental and control groups on the pre-surgery social contacts scale ($M_{Exp.\ pre\text{-}surgery}$ = 8.30±1.48, $M_{Control.\ post\text{-}surgery}$ = 9.20±1.83, p<0.01). In the area of social contacts, the items tested included relationships with friends and acquaintances ($M_{Exp.\ pre\text{-}surgery}$ = 8.8±2.11, $M_{Control.\ pre\text{-}surgery}$ = 9.40±2.11), acceptance of the individual in their circle of friends ($M_{Exp.\ pre\text{-}surgery}$ = 9.07±1.99, $M_{Control.\ pre\text{-}surgery}$ = 9.53±1.98), and social competence ($M_{Exp.\ pre\text{-}surgery}$ = 8.95±1.81, $M_{Control.\ pre\text{-}surgery}$ = 9.09±1.67). No significant differences were found between the groups. The items with a significant difference in the mean values were the loneliness of the subjects ($M_{Exp.\ pre\text{-}op}$ = 7.47±3.14, $M_{Control.}$ pre-op = 9.40±2.35, p<0.01), the fun factor with friends ($M_{Exp.\ pre\text{-}op}$ = 8.19±2.00, $M_{Control.\ pre\text{-}op}$ = 9.42±2.04, p<0.01), how well the subjects can get involved with friends and acquaintances ($M_{Exp.\ pre\text{-}op}$ = 8.21±2.02, $M_{Control.\ pre\text{-}op}$ = 9.04±1.77, p<0.05), how much they enjoy being around people ($M_{Exp.\ pre\text{-}op}$ = 8.00±2.14, $M_{Control.\ pre\text{-}op}$ = 8.96±2.07, p<0.05) and how communicative the person is ($M_{Exp.\ pre\text{-}op}$ = 8.02±2.40, $M_{Control.\ pre\text{-}op}$ = 8.89±2.20, p<0.05). The mean values of the control group were higher for all significant differences. Some item analyses showed a significant difference, and even non-significant results also showed a considerable trend.

The topic of leisure time included the items opportunities for leisure activities ($M_{Exp.\ pre\text{-}surgery}$ = 8.82±2.17, $M_{Control.\ pre\text{-}surgery}$ = 8.87±2.78), physical ability to travel ($M_{Exp.\ pre\text{-}surgery}$ = 10.27±1.01, $M_{Control.\ pre\text{-}surgery}$ = 9.78±2.43), how much the subjects liked to travel ($M_{Exp.\ pre\text{-}surgery}$ = 9.2±2.45, $M_{Control.\ pre\text{-}surgery}$ = 9.16±2.70), and how well they participated in sports ($M_{Exp.\ pre\text{-}surgery}$ = 8.48±2.45, $M_{Control.\ pre\text{-}surgery}$ = 8.91±2.72). No significant differences were found for any aspect.

It is interesting to compare what non-affected individuals expect from the consequences of surgery with what those affected by BID think.

A highly significant difference between the groups was found for the occupation scale after surgery ($M_{Exp.\ post\text{-}surgery}$ = 9.38±1.54, $M_{Control.\ post\text{-}surgery}$ = 6.20±2.75, p<0.01). In the occupation category, highly significant differences were found between the groups for the items on work ability ($M_{Exp.\ post\text{-}surgery}$ = 9.30±1.62, $M_{Control.\ post\text{-}surgery}$ = 6.09±3.20, p<0.01) and job satisfaction ($M_{Exp.\ post\text{-}surgery}$ = 9.24±2.07, $M_{Control.\ post\text{-}surgery}$ = 5.58±3.14, p<0.01). There was also a highly significant difference in the item regarding how well the subjects could perform their jobs after surgery ($M_{Exp.\ post\text{-}surgery}$ = 9.29±2.11, $M_{Control.\ post\text{-}surgery}$ = 5.87±3.51, p<0.01). All mean values were higher in the experimental group.

A highly significant difference was found between the experimental and control groups on the scale "Sex life & relationships after surgery" ($M_{Exp.\ after\ surgery}$ = 7.68±2.41, $M_{Control.\ after\ surgery}$ = 6.29±2.67, p<0.01). A highly significant difference was found for the item "Sexual satisfaction after surgery" ($M_{Exp.\ after\ surgery}$ = 8.51±2.67, $M_{Control.\ after\ surgery}$ = 5.18±3.09, p<0.01) after surgery and for the item "How well sexual activity would be possible after surgery" ($M_{Exp.\ after\ surgery}$ = 8.81±2.75, $M_{Control.\ after\ surgery}$ = 5.32±2.75, p < 0.01). A highly significant difference was also found for the item "How well would your partner react to surgery" ($M_{Exp.\ after\ surgery}$ = 5.48±3.36, $M_{Control.\ after\ surgery}$ = 7.02±2.90, p<0.01) and for the question "How strongly could the participants commit to their partner" ($M_{Exp.\ after\ surgery}$ = 9.03 ±2.78, $M_{Control.\ after\ surgery}$ = 7.44±2.97, p<0.01). No significant differences were found for the feeling of happiness in the relationship ($M_{Exp.\ after\ surgery}$ = 8.51±3.32, $M_{Control.\ after\ surgery}$ = 7.36±3.18) and for the item "How would your partner react to the changes in their body after surgery" ($M_{Exp.\ after\ surgery}$ = 6.16±3.43, $M_{Control\ after\ surgery}$ = 7.02±2.95). In all significant differences, the mean values of the experimental group were higher.

The comparison of the experimental and control groups on the social contacts scale after surgery revealed a highly significant difference ($M_{Exp.\ after\ surgery}$ = 8.88±1.61, $M_{Control.\ after\ surgery}$ = 7.62±1.83, p<0.01). Regarding social contacts, highly significant differences between the groups were found in the fun factor that the participants had with their friends ($M_{Exp.\ after\ surgery}$ = 8.88±2.18, $M_{Control.\ after\ surgery}$ = 7.04±2.51, p<0.01) and in social competence ($M_{Exp.\ before\ surgery}$ = 9.30±1.87, $M_{Control.\ after\ surgery}$ = 7.58±2.04, p<0.01). Furthermore, significant differences were found in the questions about how much the subjects enjoyed being around people ($M_{Exp.\ post\text{-}surgery}$ = 8.77±2.20, $M_{Control.\ post\text{-}surgery}$ = 7.22±2.30, p<0.01) and how well they could engage with their friends and acquaintances ($M_{Exp.\ post\text{-}surgery}$ = 9.40±1.62, $M_{Control.\ post\text{-}surgery}$ = 7.40±2.24, p<0.01). A significant difference was also found in relationships with friends and acquaintances ($M_{Exp.\ post\text{-}surgery}$ = 9.17±1.85, $M_{Control.\ post\text{-}surgery}$ = 8.13±2.39, p<0.05) and loneliness ($M_{Exp.\ post\text{-}surgery}$ = 8.26±2.95, $M_{Control.\ post\text{-}surgery}$ = 7.11±2.62, p<0.05). No significant differences were found in terms of acceptance among friends ($M_{Exp.\ post\text{-}surgery}$ = 9.05±2.18, $M_{Control.\ post\text{-}surgery}$ = 8.47±2.40) or in terms of how communicative the participants rated themselves ($M_{Exp.\ post\text{-}surgery}$ = 8.58±2.27, $M_{Control.\ post\text{-}surgery}$ = 7.93±2.29). In all significant mean differences, the mean values of the experimental group were higher.

93.3% in both, the experimental and control group, reported having hobbies. In the experimental group 29(64.4%) reported participating in sports, and in the control group 35(77.8%) reported doing sports. In the leisure category, all mean comparisons were highly significant ($p<0.01$). This is evident in the possibilities for leisure activities ($M_{Exp.\ post\text{-}surgery} = 8.69\pm2.23$, $M_{Control.\ post\text{-}surgery} = 5.48\pm2.37$) and in the physical possibilities to travel ($M_{Exp.\ post\text{-}surgery} = 9.38\pm1.95$, $M_{Control.\ post\text{-}surgery} = 5.73\pm2.54$) and in the question of how much the people would like to travel ($M_{Exp.\ post\text{-}surgery} = 9.31\pm2.43$, $M_{Control.\ post\text{-}surgery} = 6.73\pm3.17$) and do sports ($M_{Exp.\ post\text{-}surgery} = 8.18\pm2.45$, $M_{Control.\ post\text{-}surgery} = 3.77\pm2.45$), how strongly the subjects consider their limitations in leisure activities ($M_{Exp.\ post\text{-}surgery} = 7.29\pm2.95$, $M_{Control.\ post\text{-}surgery} = 4.91\pm2.63$) and how well they could pursue their hobbies ($M_{Exp.\ after\ surgery} = 8.93\pm2.54$, $M_{Control.\ after\ surgery} = 4.89\pm3.0$). In all mean comparisons, the mean values of the experimental group were higher.

Discussion

This study aimed to determine whether people with BID believe they are more satisfied after surgery. The results confirm that the tested individuals with body integrity dysphoria hope to be more satisfied with their jobs, relationships, and social contacts after surgery. They do not perceive a physical disability as a limitation in their leisure activities.

These results confirm previous studies. Noll and Kasten [20] also showed that those affected feel better in their personal and professional lives after surgery, and that their general living situation improves significantly.

When compared with a control group without BID, it was clear that those affected by BID are under a great deal of stress, as they are worse off in almost all areas than the control group. One important aspect, for example, was their ability to work.

The quality of life of those affected by BID is severely limited by ruminations. They believe that this rumination will disappear after surgery, allowing them to focus more on work, family, and friends. This was also clearly evident in the fact that the subjects stated that they believe they are significantly more focused on work and private life after surgery. The BID subjects believe they would be significantly more satisfied with their sex life after surgery and would be able to engage much more with their partner, friends, and acquaintances. Those affected by BID believe they will feel less lonely after the amputation, which could potentially reduce the risk of depression and significantly improve their quality of life.

The results regarding work ability and job satisfaction are also particularly important. From the perspective of BID patients, there would be no disadvantage for the working world and, above all, for the financial situation of those affected, because they believe they would be able to work better and be happier after surgery. Furthermore, they would not be a financial burden for the government. Those affected stated that they had no restrictions on their leisure activities after surgery. The reason for this could be that they could use prosthetics for sports or switch to another sport. For many hobbies amputation of a leg would not be an obstacle at all anyway.

The significantly lower values after surgery in the control group can be explained by the fact that the people in the control group did not desire a physical disability because they did not believe they would then have a complete self-image. They do not view a disability as a challenge, as many BID patients do, but rather as a burden. For those affected by BID, surgery is the life-saving solution; for healthy people, it significantly impairs the lives of those affected. BID- affected have a different perspective on physical disability than the control group.

Could amputation be a possible solution for BID? On the one hand, this question could be answered in the affirmative, since no alternative therapy has been found so far and patients suffer greatly, resulting in extremely limited quality of life. On the other hand, however, too little research has been done in the field of alternative therapies to be able to say that there is no therapy for BID. However, every person has the right to freely shape their body. For example, gender reassignment surgery or tattoos and piercings can be done. So where are the limits of this right? With a tattoo, piercing, or gender reassignment, the body remains fully functional, but not with BIID surgery. This is probably the main reason why doctors refuse to perform such operations. It contradicts the morality of doctors, who actually want to provide the best possible care for their patients and do not want to cause harm. Cosmetic surgery contradicts this. Doctors do not want to harm, but the risks of cosmetic surgery are not small [2,16]. The Declaration of Helsinki stipulates that new, less frequently performed methods may be used with the patient's consent. This presumes that the patient will experience greater well-being after the procedure. This would most likely be the case with BID, which this study confirms. Furthermore, every patient has a right for self-determination and autonomy. Patient needs must be taken seriously and fulfilled whenever possible to achieve the greatest possible well-being for the patient.

One argument in favour of surgery is the fact that many affected individuals injure themselves to obtain the desired operation. This poses a high health risk. This risk could be minimized by legalizing the operations and ensuring that the procedure is performed in a controlled manner.

Another important aspect is the cost of surgery. Depending on which part of the body is removed or the type of procedure performed, the home may need to be remodelled, a nursing assistant may need to be hired, and doctor visits may increase. On the other hand, those affected are so burdened by the disease that they cannot, for example, work properly. This could be improved through surgery, which was also reflected in the results.

Conclusion

In summary, few studies have been conducted with individuals who have already undergone amputation. This study shows that those affected hope for improvement in many areas, but none of these participants had already undergone surgery. However, the test subjects were probably able to put themselves in the situation after an operation very well, as they spent a lot of time thinking about it and imitating the situation beforehand and weighing up the pros and cons.

Declarations

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Institutional review board statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Ethics Committee of the Medical School Hamburg.

Informed consent statement: Written informed consent has been obtained from all participants to publish this paper.

Data availability statement: The original data can be obtained from the author upon request.

Conflicts of interest: The author declares no conflict of interest.

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