

## Body Integrity Identity Disorder: A review of current knowledge and management options

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### Abstract

Body Integrity Identity Disorder (BIID), also known as body integrity dysphoria and xenomelia is a rare chronic psychiatric condition characterized by an intense and persistent desire to have one or both healthy limbs amputated or paralyzed. Affected individuals usually experience discomfort with being able-bodied.

This disorder often causes significant distress and decreased quality of life, with patients believing they would be happier living as an amputee, sometimes mutilating themselves. Though very rare, most sufferers fail to complain to clinicians due to the embarrassing nature of their bizarre desire. As a result, the disorder is infrequently studied and lacks standardized diagnostic criteria and formal guidelines for psychotherapy or pharmacotherapy, underscoring the need for investigation and extensive empirical research.

This study reviews the current knowledge and management of BIID to encourage recognition by the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Disease (ICD).

**BIID; disorder; xenomelia; dysphoria; treatment**

### INTRODUCTION

Body Integrity Identity Disorder (BIID) is a rare condition where individuals present with an intense and persistent desire to have one or both of their healthy limbs amputated or paralyzed [1-3]. This lifelong and obsessive desire often leads to distress and decreased quality of life [4-6]. The desire for amputation or paralysis is presumed to arise from a mismatch between the individual's mental representation of his/her body and the actual physical structure

of the body [4-6], hence the primary reason for their desire is to feel complete and satisfied inside and have a restored identity [4,8]. It should be noted that these individuals are not psychotic and are fully aware that the said limb is perfectly healthy but complain of overcompleteness and need amputation or paralysis.

The first amputation of a BIID patient was performed by Robert Smith [9] and though participants in subsequent researches who have had amputation have shown positive outcomes [1,10-12] there has been public outcry and even criticism by the medical ethicist, Arthur Caplan [13,14].

Due to the embarrassment experienced by those with BIID from having the bizarre desire, they rarely present themselves to medical professionals. This has resulted in a lack of proper

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investigation of this disorder and its lack of recognition by WHO [1,4]. There is a website where sufferers share experiences and suggest relatively painless and safe ways to damage the limb, often leaving surgeons no option other than to carry out the limb amputation [9].

This study is a comprehensive review of the current knowledge and management of BIID. Considering the significant consequences of BIID on its sufferers, this comprehensive study will encourage its inclusion in the next edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Disease (ICD).

## EPIDEMIOLOGY

Though there is a paucity of research on this subject, in recent years cases have been increasing [15-19]. BIID mostly affects males and manifests before adolescence, and their desire for amputation or paralysis is mostly for the lower limbs [4,20].

In First's study [1], 47 of the 52 participants were males while four were females and one intersex individual. Blanke and colleagues [21] had 20 participants with 17 males and three females. Kasten [22] had 9 participants, all-male. Johnson and colleagues [23] had 72 participants, of which only 8 are women. Noll and Kasten [25] with 18 participants had only 3 women.

The paralyzation variant, though affecting a higher percentage of females [6,20], has the same BIID features [6,20,25,26]. All those with the paralyzation variant only seek to paralyze the limbs, and they keep the urogenital tract functions intact [7].

BIID is not yet endorsed as a real medical condition with defined diagnostic criteria and treatment options. Consequently, it is not possible to conduct a truly epidemiological study that will record the incidence and the characterization of the disorder [2].

## AETIOLOGY

It has been suggested that in BIID, the presence of a mismatch between an individual's perceived mental representation and his/her actual

physical structure leads to the desire of becoming an amputee or becoming paralyzed. The results from the work of Blom et al. [27] show a reduction in grey matter volume in the left dorsal and ventral premotor cortices and also an increase in the grey matter volume in the cerebellum of individuals with BIID. These two areas of the brain are thought to be responsible for the experience of body ownership and the integration of multisensory information. Several magnetic resonance imaging (MRI) studies done on individuals with BIID have hypothesized the presence of abnormalities in the frontoparietal/body ownership network, making the individual have feelings of over completeness with the four limbs [15,19,27,28]. It appears the patient experiences a negative phantom limb since the affected limb, though physically present and normal, is experienced as if they're over present and lack animation. Though many of these studies focused on BIID as a neurological condition [15,29], some other studies show that many of the associated signs point to significant social co-determinants [5,30]. Importantly, though these studies have reported the presence of an altered central network involving the body representation of the legs, its relationship to behavior remains unclear in BIID [31].

## SYMPTOMS

Individuals with BIID experience a lifelong obsessive desire to be amputated or paralyzed. These thoughts distress many of them and consequently lead to the disruption of their social life and make them distracted at work [32]. Most study participants first noticed the symptoms in early childhood and the main reason for their desire is to feel complete and satisfied inside [4,8,20]. Some participants also report sexual attraction or admiration for other amputees [1,33]. However, this admiration or attraction is not the primary reason for seeking amputation or paralyzation in a person with BIID.

It is unusual to see somatic and severe psychiatric co-morbidity, although the enormous distress caused by BIID could lead to depressive symptoms and mood disorders [4]. These patients are not psychotic, and they fully understand their request. They describe having a feel-

ing of alienation [28] and identify internally as amputees.

Their desire is so strong that even when they are repeatedly denied surgeries, they would take the matter into their hands looking for relatively painless ways to amputate the limbs [5].

## DIAGNOSIS

Generally, psychiatric syndromes are defined by the typical signs displayed and the symptoms reported by the sufferers. Almost all entry in DSM is also of this form [34].

Currently, BIID is not officially listed as a diagnosis in the Tenth Revision of the International Classification of Disease though it is set to be included in the Eleventh version as Body Integrity Dysphoria [35]. It is also not included in the current edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

Most studies by current literatures [1, 2, 4, 17, 20, 36] use the criteria proposed by First [1] or Ryan [34]:

1. Presence of strong persistent desire to be disabled or amputated.
2. The primary reason or motivation for desiring amputation or paralysis is to achieve one's true and proper body identity. Thus the primary motivation is not sexual arousal or any advantage one might enjoy by being disabled.
3. The desire causes such significant distress that there could be impairment in the individual's occupational, social, or other important areas of functioning
4. The disorder cannot be explained better by any other medical condition, or any psychiatric conditions like psychosis, body dysmorphic disorder, or somatoparaphenia.

The second criterion would help us differentiate apotemnophilia, a condition where people primarily desire amputation for sexual gratification, from BIID. First [1] however reported a considerable overlap between apotemnophilia and BIID.

The fourth criterion helps us to exclude other conditions that might be mistaken for BIID [34].

## MANAGEMENT

There is currently no recognized official guideline for the treatment of BIID. The treatment options below are those proposed or used in case reports. We have done a careful review to determine and present the effectiveness of each of the options.

1. **Psychotherapy:** This treatment option has often been tried. Most respondents (65%) in First's [1] survey reported they had undergone psychotherapy at a point in their life. However, none reported having had a reduction in the desire for amputation or paralysis.

Blom et al. [4] reported that psychotherapy, though supportive, does not help in diminishing BIID symptoms.

In a study by Braam et al. [37], they described a patient who had attended 30 sessions of cognitive-behavioral therapy (CBT). The patient had had a reduction in the level of distress experienced from BIID throughout the therapy. However, this reduction was related to the patient's ability to share his burden of BIID with others. There was also no evidence of improvement for the underlying desire for amputation.

2. **Psychopharmacology:** Taking antidepressants help reduce depression symptoms in BIID but antipsychotics do not seem to have any effect on it [4].

First reported that 40% of his respondents had had psychotropic medications at some point in their life. Most of them took either clomiphen or selective serotonin reuptake inhibitor (SSRI). Though there was an improvement in their mood, there was no appreciable effect on the desire to be amputated.

Braam et al [36] also reported that the addition of 20 mg of paroxetine, an SSRI, reduced the distress associated with BIID.

Berger et al. [38] however reported a decrease in the desire to be amputated when fluoxetine, another SSRI, was used in a higher dose (60mg).

3. **Vestibular Caloric Stimulation:** Vestibular Caloric Stimulation, a procedure that involves the flushing of an individual's ear with cold water, was proposed by Ra-

machandran and McGeochdue due to its effect on patients with somatoparaphrenia [39]. Leggenhager et al. [30] in their work on 13 subjects noted that the desire for amputation does not diminish with vestibular caloric stimulation. Thus, this is currently speculation.

4. **Amputation:** Amputation of healthy limbs lead to remission of BIID symptoms and improves patients' quality of life [4]. Robert Smith is the first to perform amputation for BIID patients. Both patients were said to have had their lives transformed for the better and satisfied with the surgery [10,11]. Nine of the 52 participants in First's survey, who had had amputation, expressed satisfaction with the result. Noll and Kaslen [24] also reported an increase in satisfaction and flourishing among their respondents. Even those with complications do not regret requesting amputation. One respondent who now lives permanently with orthotics or wheelchair after his amputation said he now lives his life every day free of burn-out, depression, and now meet friends without anxiety. The 7 respondents who had had amputation in the work of Blom et al. [4], claimed that amputation was effective. These 7 respondents scored lower significantly on the Sheehan Disability Scale compared to those who had not had an amputation for their BIID. Also, the works of Taylor [40], Berger et al. [38], Johnson et al. [23], and Furth and Smith [41] reported satisfaction and flourishing among those who had had amputation in BIID patients.

BIID symptoms can be very distressing and frustrating that some resort to taking matters into their hands, while others may turn to incompetent doctors after being denied amputation by competent doctors. Among the 52 participants in First's survey, 6 had amputated a limb themselves. They used dangerous means including a shotgun, a wood chipper, and a chainsaw. A 79-year-old man in 1998 died of gangrene after being amputated in a black market where he paid \$10 000 [42]. Those who cannot find a willing surgeon or even pay the price for amputation may resort to mutilating themselves by sawing a finger or toe off, packing the body part in dry ice in

an attempt to freeze it to death, or even shooting into the leg [9,38,43].

From the foregoing, it is evident that amputation is the most effective mode of management of BIID. Despite this, amputation remains the most controversial. Some scientists and medical ethicists have strongly condemned it. Other scientists, however, have spoken and argued in its favor [9,34,44].

In medical ethics, autonomous desire ought to be regarded with all seriousness. Since patients with BIID meet reasonable standards for autonomy and rationality, surgeons ought to assent to their request since there is no other effective treatment for their condition.

## CONCLUSION

BIID is a disorder characterized by feelings of overcompleteness and obsessive desire to amputate or paralyze a healthy limb. This desire does not stem from the need for sexual gratification and individuals experience depression and inability to concentrate on work. The aetiology of the disorder has been suggested to be from neurological conditions alongside social co-determinants. Most literature use the criteria proposed by First and Ryan for the diagnosis as it is not listed in most disease classifications including DSM-V and the International Classification of Disease. Pharmacotherapy and psychotherapy have been found to be useful in the management of BIID but amputation proved most effective.

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