



Amputation: does it treat body integrity dysphoria?

Rini Yunia Andalia¹ and M. Surya Husada¹

¹Department of Psychiatry, Faculty of Medicine, Universitas Sumatera Utara, Medan, North Sumatra

Corresponding author: surya.husada@usu.ac.id

Abstract. This case report illustrates Body Integrity Dysphoria (BID). The patient, A 25-year-old right-handed male, experienced profound distress over his left foot's third and fourth fingers. Despite unsuccessful non-invasive treatments, he sought elective amputation of these fingers. The decision for surgery was made considering the patient's persistent desire, potential risks of self-harm, and the specific involvement of two fingers rather than a whole limb, despite ethical concerns and limited BIID literature. Following the amputation, the patient immediately experienced relief: nightmares ceased, emotional distress lessened, and functionality improved. This case underscores the potential effectiveness and patient satisfaction of elective amputation in specific BID cases. It sheds light on the unique challenges faced by affected individuals and emphasizes the importance of understanding, support, and inclusive healthcare practices.

Keywords: amputation, body dysmorphic disorder, body dysphoria, psychotherapy

1 Introduction

Body Integrity Dysphoria (BID), formerly known as Body Integrity Identity Disorder (BIID), affects individuals who feel that a limb is not part of their body. Despite being able to feel, use, and move the limb, they cannot reconcile its presence as part of themselves, sometimes leading to thoughts of self-amputation, which poses significant risks.^{1,2} Elective amputation of non-diseased functional body parts, such as limbs or digits, raises ethical dilemmas regarding patient autonomy. The limited literature on BID complicates the development of clear guidelines and recommendations. Many patients hesitate to seek help from healthcare professionals and instead turn to online communities for advice, making it difficult to accurately determine BID's prevalence. Nevertheless, surgical intervention remains a potential treatment for this rare condition and should be considered thoroughly.^{2,3} Here we present a case of a patient with BID in order to participate demonstrates the analysis of this specific case, allowing for a comprehensive diagnostic and management process.

2 Case History & Examination

A 25-year-old right-handed male who works as a machinist presents with a strong desire to have the third and fourth toes of his left foot amputated. Despite recognizing these toes as his own, he has felt that they do not belong on his body since adolescence. The patient reports a long-standing discomfort and disassociation with his third and fourth toes, which he has felt since he was a teenager. He hides these toes by keeping them

curled, which has led to significant difficulty in walking, localized pain, irritability, and frequent bouts of anger. His sleep is often disturbed by vivid nightmares where he sees his toes decaying or being engulfed in flames. He also suffers from daily intrusive thoughts that his toes are foreign to him, causing severe emotional distress and a persistent belief that they should not be part of his body. Due to the distress caused by these toes, the patient appears anxious and distressed. However, he discusses his condition and its implications for surgical intervention with a clear and serious demeanor. He has not disclosed his feelings to his family out of embarrassment and fear of not being understood. The patient experiences constant internal conflict and trauma because of the presence of these toes. He seeks surgical amputation as a means to reconcile his physical appearance with his mental self-image and to achieve relief from the distressing thoughts and sensations that these toes provoke. He also wishes to avoid the potential danger and psychological toll of attempting self-amputation. Despite his intense desire for removal, the patient is aware of the potential risks and consequences of self-harm. He had considered asking a colleague to monitor him in case he attempted self-amputation and had even thought about constructing a device to remove his toes at work. However, he recognizes the dangers associated with self-harm, including health risks and potential damage to his relationships and reputation.

3 Methods

Participants were recruited from the psychiatric outpatient clinic of a general hospital. A 25-year-old right-handed male working as a machinist presented with a desire for the amputation of the third and fourth toes on his left foot. The primary care physician, who had a long-standing history with the patient, facilitated the referral. The patient's informed consent form has been duly obtained, ensuring that they fully understand the nature and purpose of the case report. The patient has been informed about the potential implications and the details of the reporting process, and they have expressed no reservations or objections. Their agreement to participate demonstrates their willingness to contribute to the documentation and analysis of this specific case, allowing for a comprehensive and transparent reporting process.

Thorough diagnostic evaluations were performed, encompassing both initial and follow-up interviews conducted by a general psychiatrist. The evaluations comprised detailed patient history reviews, including family history and substance use assessment. Brain imaging was performed to rule out neurological abnormalities, with results indicating normal brain function. Chart reviews were conducted, encompassing all available medical records and imaging studies. No specific questionnaires were administered during the diagnostic process.

Follow-up visits were scheduled to monitor the patient's condition and reassess his desire for amputation. These visits confirmed the consistency of his symptoms and the persistence of his request. Throughout the evaluation process, the patient exhibited

strong motivation and a serious demeanor, seeking a resolution for his condition. The patient's compliance and engagement were documented at each visit.

The methodology aimed to ensure a thorough and comprehensive understanding of the patient's condition. It leveraged clinical interviews and imaging studies to support the diagnosis and track the patient's ongoing mental and physical health status.

4 Outcome & Follow Up

After receiving cognitive-behavioral therapy (CBT) and pharmacotherapy with Fluoxetine (up to 80 mg) and Aripiprazole (15 mg daily), which he tolerated well despite mild sedation over seven months, the patient's distress heightened during therapy sessions that included exposure, mirror exercises, and desensitization. While he was convinced that amputation was the ideal solution, he initially agreed to try non-invasive methods linked to his condition related to gender dysphoria.

After being assessed as mentally capable of deciding on amputation, he was referred to an orthopedic surgeon and, in consultation with his psychiatrist, adjusted his psychotropic medications. Although he felt some relief from the orthopedic referral, he still harbored doubts about potential outcomes. 24 weeks later, he underwent elective amputation at his local hospital, reaffirming his consent and desire for the procedure. After the surgery, He experienced immediate relief from nightmares and emotional distress. Surgical pain diminished within a week, and there were no reports of phantom pain during the one-month follow-up. His functionality remained unaffected.

He reported reduced anger, improved family and workplace well-being, formulated life plans, and expressed no regrets. He disclosed concerns about potential romantic relationship judgment and managed his disclosures accordingly. Follow-up visits confirmed his ability to enjoy a normal life.

Beginning with noninvasive methods, he affirmed that overcoming significant finger-related suffering bolstered his confidence in facing future challenges. Collaboration, the absence of comorbidities, and documented cases facilitated straightforward surgical recommendations. Involvement limited to two fingers eased medical team decision-making. Emotional responses and evaluations substantiated his informed decision-making capacity. Despite initial uncertainties, he engaged closely with orthopedic teams, ensuring prompt psychiatric-driven treatment following less successful medication and psychotherapy attempts.

Psychotherapy, compared unfavorably in tolerability and duration of distress, exacerbated dysphoria despite persistence toward finger-related relief. Short-lived postoperative pain effectively resolved the primary issue, enabling anticipated life quality without finger-related concerns. Pharmacotherapy offered inadequate relief and sedation, with outweighed risks for young clear BID presentations.

5 Discussion

One of the earliest recognized instances of Body Integrity Dysphoria (BID) was labelled apotemnophilia by Money in 1977.¹ This syndrome involves intrusive and intense thoughts centered on the wish to amputate a healthy body part, such as an arm or a leg. One prevalent hypothesis proposes that this disorder emerges from a perceived discrepancy between an individual's body schema and physical reality, prompting them to view amputation as essential to their identity.^{2,3} Although there is currently insufficient evidence and long-term efficacy studies to advocate surgery as a primary treatment option, it has been noted to successfully address BID, often resulting in high patient satisfaction. Individuals with BID do not typically experience delusions; they acknowledge the affected limb as their own but perceive it as incongruent with their body schema or sense of identity, a sentiment typically present since childhood. Various presentations have been reported in the literature, ranging from typical BID cases to variants or subsets, including preferences for paralysis over amputation, which is more prevalent among women, or even violent behaviors such as attempted self-amputation, more common among men, influencing reported cases.²⁻⁴

Given the patient's characteristics documented in this case align with those seen in the existing literature and considering the potential risks associated with not offering surgery—including death from self-harm attempts—the decision was made to proceed with surgical intervention despite the absence of guaranteed symptom remission.^{1,2} A notable distinction from many reported cases is that the patient's distress centered on two digits rather than a complete limb, somewhat facilitating the medical team's decision-making process. This observation prompts consideration of a potential selection bias, wherein more severe or impactful limb impairments may lead to increased reporting and awareness of BID cases involving complete limbs.^{3,5,6}

Grey matter atrophy has been observed to be associated with compensatory behaviors in BID, though whether this relationship signifies the cause or effect of symptom intensity remains unclear. The boundaries of dysphoria-inducing regions are clearly defined, evidenced by decreased skin conductance reactions noted under the areas where amputation is desired.⁷ Unlike body dysmorphic disorder, where surgery is often discouraged due to perceived flaws, individuals with BID do not necessarily perceive their affected limb as aesthetically unappealing or diseased. Even when aesthetic concerns are present, they typically do not serve as the primary motivation for seeking amputation.^{4,8} In this particular instance, the patient conscientiously evaluated the possible cosmetic alterations and the consequences of undergoing amputation, balancing these considerations with a profound desire to harmonize with their perceived body image. Ultimately, he prioritized this alignment over concerns about societal judgment in relationships, work, or leisure activities. This decision-making process also reinforced acceptance by those around him of his true identity.

Analogies have been drawn between Body Integrity Dysphoria (BID) and conditions such as anorexia nervosa and gender dysphoria, where surgery is generally approached

with caution due to potential risks. In this study, the patient identified similarities between their own experience and that of individuals undergoing surgical treatments for gender dysphoria, feeling they exhibited characteristics reminiscent of post-traumatic stress disorder (PTSD).^{6,7}

Amputating a healthy limb due to psychological distress is a rare event. Critics frequently cite the Hippocratic principle of "First, do no harm" in response, citing concerns over potential regret, disability, or financial burden associated with such procedures. However, individuals suffering from Body Integrity Dysphoria (BID) endure profound distress, sometimes resorting to self-amputation or seeking illicit procedures. The risks involved, including death, underscore the pathology that arises when an individual's adaptive capacities are overwhelmed. Being outside societal norms does not automatically imply dysfunction or disease.^{8,9} Amputation aligns with medicine's goal of promoting health and adaptation by improving functional abilities and alleviating suffering related to identity or body image. Resistance to change may hinder efforts to promote health, which can be defined by either the typical biological functioning of the body or an individual's capability to adjust to their circumstances. Individuals with BID seek changes through informed consent, demonstrating capacity for decision-making and seeking improvement in overall functioning. In some cases, surgical intervention effectively relieves their suffering, theoretically facilitating a smoother transition compared to traumatic, unplanned amputations. However, empirical evidence supporting this is limited, including documentation of long-term outcomes.^{5,9,10}

For patients not suffering from delusions, amputation may not violate the principle of non-maleficence if it relieves psychological distress without additional harm or disability. This approach may help align their physical body with their mental image of it, reflecting their efforts and adaptations in utilizing, abstaining from using, or simulating the absence of the body part they feel is not their own. Collecting more evidence demonstrating high levels of satisfaction and enhanced quality of life could encourage patients and healthcare providers to consider intervening sooner. This includes factoring in the costs associated with managing depression and dysfunction linked to BID, as well as exploring less invasive supportive treatments like pharmacotherapy and psychotherapy.^{11,12} In individuals with BID, changes in how they perceive their limbs and their avoidance of using them can cause limb weakness. Pretending to have amputation or paralysis may reduce productivity, limit participation in leisure activities, and affect social interactions, thereby increasing the likelihood of injury and engaging in risky behaviors.^{10,13}

Nevertheless, some individuals find that employing these coping strategies helps them bring their perceived body representation closer to their desired state, thereby reducing distress. In the scenario outlined, attempts at pretense resulted in localized pain, and the coping mechanisms employed were ineffective in alleviating distress. Ultimately, surgery provided the patient with a highly satisfying and successful treatment.^{5,12}

6 Conclusion

This case represents an elective digit amputation, providing a clear example of a clinical presentation of Body Integrity Dysphoria (BID). After unsuccessful attempts with noninvasive treatments, the patient clearly experienced significant benefits from elective surgery. Now, he no longer experiences distressing preoccupation regarding his fingers, as all symptoms associated with BID have been resolved. The amputation enabled him to integrate his life with his perceived identity, deepening his recognition of the magnitude of his suffering and enabling effective communication with his medical team.

Sharing knowledge regarding BID can profoundly impact individuals experiencing the condition by promoting comprehension and support from healthcare professionals. This presents an occasion to promote healthcare inclusivity by expanding health definitions using diverse models. Acknowledging and meeting the unique needs of these patients can lead to a future where they enjoy increased dignity, respect, and overall well-being.

References

1. Becker D. Unpublished Masters' Thesis. Medical School Hamburg (MSH), University of Applied Sciences and Medical University; Hamburg, Germany: 2019. Erklärungsansätze zur Body Integrity Dysphoria. [Google Scholar]
2. Chakraborty S, Saetta G, Simon C, Lenggenhager B, Ruddy K. Could brain-computer interface be a new therapeutic approach for body integrity dysphoria? *Front Hum Neurosci.* 2021;15:699830.
3. Garbos M., Kasten E. Inventory for the Assessment of the Severity of Body Integrity Dysphoria (BID Assessment) Arch. Assess. Psychol. 2022;12:77–89. [Google Scholar]
4. Gibson RB. The desirability of difference: Georges Canguilhem and body integrity identity disorder. *J Med Philos.* 2022;47(6):711-722.
5. Gibson RB. Body integrity dysphoria and medical necessity: amputation as a step towards health. *Clin Ethics.* 2023:14777509231160398. doi:10.1177/14777509231160398
6. Gibson RB. Elective impairment minus elective disability: the social model of disability and body integrity identity disorder. *J Bioeth Inq.* 2020;17(1):145-155.
7. Lebelo L.T., Grobler G.P. Case study: A patient with severe delusions who self-mutilates. *S. Afr. J. Psychiatry.* 2020;26:1403. doi: 10.4102/sajpsychiatry.v26i0.1403. [PMC free article] [PubMed] [CrossRef] [Google Scholar]
8. Saetta G., Hänggi J., Gandola M., Zapparoli L., Salvato G., Berlinger M., Sberna M., Paulesu E., Bottini G., Brugger P. Neural Correlates of Body Integrity Dysphoria. *Curr. Biol.* 2020;30:2191–2195. doi: 10.1016/j.cub.2020.04.001. [PubMed] [CrossRef] [Google Scholar]
9. Salvato G, Zapparoli L, Gandola M, et al. Attention to body parts prompts thermoregulatory reactions in body integrity dysphoria. *Cortex.* 2022;147:1-8.
10. Saricicek B. Unpublished Bachelor's Thesis. Medical School Hamburg (MSH), University of Applied Sciences and Medical University; Hamburg, Germany: 2021. Body Integrity Dysphoria (BID)—Ist das Erreichen der Körperbehinderung Langfristig Erfolgversprechend? [Google Scholar]
11. Scupin C., Schnell T., Kasten E. How determined is the gender identity in people suffering from Body Integrity Dysphoria (BID) Adv. Mind Body Med. 2020;35:17–32. [PubMed] [Google Scholar]

12. Tabesh M. Unpublished Masters' Thesis. Medical School Hamburg, University of Applied Sciences and Medical University; Hamburg, Germany: 2023. Experimentelle Untersuchung der Schmerzwahrnehmung bei BID-Betroffenen. [Google Scholar]
13. Turbyne C, Koning P, Zantvoord J, Denys D. Body integrity identity disorder using augmented reality: a symptom reduction study. *BMJ Case Rep.* 2021;14(1):e238554

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