

Desire to be disabled: body integrity identity disorder



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Body Integrity Identity Disorder (BIID) is a rare phenomenon in which individuals desire to become disabled through the amputation of fully functioning limbs. BIID is described as the disparity between the individual's perception of their body and the actual form of their physical body (Bayne & Levy, 2005). Other psychological disorders and classifications have been linked to BIID, including Gender Identity Disorder, Body Dysmorphic Disorder, and Hypochondriasis. The neurological origins of BIID are unknown at this time, and treatment of this condition through elective amputation is highly controversial. As a clinical audiologist, it is important to recognize symptoms of BIID in patients, as well as being aware of the possible treatment of BIID through vestibular testing. Arguments for and against elective amputation will also be discussed, as well as differential diagnoses of BIID.

Audiology and BIID

As a clinical audiologist, coming into contact with a patient who has Body Integrity Identity Disorder (BIID) is rare. However, the possibility does exist and it is important to understand the characteristics if one should encounter a BIID patient. The awareness of BIID in the audiology field can come into play concerning treatment of BIID, with one possible option incorporating aspects of vestibular testing.

Body Integrity Identity Disorder

“ John first took leftover prescription painkillers and numbed his left foot in ice water to reduce impending pain. He then buried his foot in dry ice for six hours to induce severe frostbite and force surgeons to operate” (Adams, 2007).

The previous insert from William Lee Adams' article, *Amputee Wannabes*, describes a 33-year-old man's wish for amputation of his foot. There was nothing physically or medically wrong with this limb; John only stated that he did not feel comfortable with his own body and felt as though his foot was not a part of him. After causing severe frostbite to spread throughout his foot, John's leg was amputated above the knee. Post-surgery, he went on to describe that the operation resolved his anxiety and allowed him to be at ease in his own body (Adams, 2007).

What causes someone to desire amputation of a healthy limb? This desire was first reported by French surgeon Jean-Joseph Sue in 1785 (Lawrence, 2006). However, this delusion only began to receive public attention in the early 2000s due to the increase in documented cases. Soon thereafter, a psychiatric condition titled Body Integrity Identity Disorder (BIID), previously known as Amputee Identity Disorder (AID), became the more favorable diagnosis for these individuals. Currently, it is estimated that only a few thousand people worldwide are afflicted with BIID (Henig, 2005). BIID is described as a disparity between the individual's perception of their body and the actual form of their physical body (Bayne & Levy, 2005). A common complaint of these individuals is that the limb is 'alien' and feels as though it is not part of them. Remarkably, those with BIID are often free of psychological issues, outside of their desire for amputation. Many are of normal intelligence, have families, and hold jobs such as lawyers, professors, and doctors (Henig, 2005). So what triggers these seemingly normal individuals to desire amputation?

The neurological origins of this disorder are unknown, yet those with BIID share similar backgrounds. Most are exposed to an amputee at a young age, usually before they are 4 years old, and the fascination stems from this encounter. They begin to experience discomfort with their own bodies, and the delusion is full-blown by the time they reach puberty. As the leading BIID researcher at Columbia University, Michael First believes that these individuals encounter an amputee while they are still in the developmental stage in which normal individuals come to accept the existence of their own arms and legs. He believes the sight of an amputee prevents such acceptance (Adams, 2007).

Although the neurological cause of BIID is unidentified, many associations have been made between BIID and other psychoses in order to narrow down the diagnosis. Whether this disorder occurs because of a single experience during childhood, or stems from a combination of other psychological conditions, it is important to discuss other closely related diagnoses of BIID.

Differential Diagnoses of BIID

Some professionals, such as Michael First, have suggested that BIID may involve a similar psychological desire as is seen in Gender Identity Disorder (GID), better known as transsexualism (Lawrence, 2006). GID is a condition in which “wrong embodiment” is the main concern. More commonly, a male patient feels as though they are a female trapped in a male’s body. In both BIID and GID, dissatisfaction with one’s own body occurs because their body part in question disagrees with their perceived sense of self (Müller, 2009).

This displeasure, as well as the desire for amputation, is the commonality of BIID and GID.

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Similarities also exist between BIID and a condition known as Body Dysmorphic Disorder (BDD). The desired outcome of those with BDD is also amputation, but these individuals mistakenly believe that a part of their body is disease-ridden or remarkably ugly. BDD ties in closely to anorexia nervosa, being that they are both delusions based on misguided perceptions of one's own body (Bayne & Levy, 2005). On the contrary, the only grounds for amputation for those with BIID revolved around the fact that the body part felt 'foreign,' despite the individual's knowledge that the limb was perfectly healthy.

Desiring a Disability

Individuals who are suffering with BIID have also been associated with individuals who desire to become disabled, or truly believe they are disabled or sick when they are not. One such disorder is known as Hypochondriasis, with the term "hypochondriac" being used more often for these individuals. Hypochondriasis is a psychiatric disorder where an individual constantly fears that they have or, at some point, will have a serious disease, even when there is no medical proof or diagnosis (Hypochondriasis, 2002). These individuals misinterpret their physical feelings as symptoms of a serious disease, similarly to those with BIID who misinterpret their healthy body part as not being part of them. Symptoms that hypochondriacs face are also similar to those with BIID, including severe anxiety and depression. Hypochondriacs are not fabricating their symptoms, and become extremely concerned with minor problems such as excessive sweating, dizziness, and occasional tinnitus (Hypochondriasis, 2002). Hypochondriasis can also be as

socially debilitating as BIID, in that it also causes individuals to not function at work or in their daily lives.

Another phenomenon associated with the desire to be disabled is known as non-organic hearing loss (NOHL). NOHL is described as “ responses to a hearing test indicating a deficit greater than can be explained by organic pathology” (Austen & Lynch, 2004). Some motives for NOHL behavior include monetary and personal gain, such as being involved in a car accident and fabricating a hearing loss as a conjunctive injury. However, not all individuals who are labeled as NOHL are malingering; some truly believe they have a hearing loss, or do not respond to the audiological testing even though their hearing sensitivity is normal. There are also those known as “ deaf wannabes,” who, much like “ amputee wannabes,” desire to belong to a community that is based on the disability or disorder. “ Deaf wannabes” may have grown up in the deaf community, and although they have normal hearing sensitivity, wish to be deaf themselves.

Overall, these conditions listed above may or may not be exclusive. An individual may not suffer from desired amputation based solely on the condition of BIID, BDD, or GID alone. Rather, they may suffer from a variety of combinations of these disorders, including Hypochondriasis and NOHL. With NOHL as a possible association, audiologists may be included in the group of professionals who interact and help with the treatment of these patients. That being said, the associations of these disorders and the knowledge that they are closely linked may lead to the best possible diagnosis of individuals who suffer from a desired disability.

Arguments in Favor of Healthy Limb Amputation

Many individuals who suffer with BIID believe that amputation is the only option. Upon learning of BIID, most people would consider it a psychotic disorder that by no means should be solved through elective amputation. However, the argument for permission of amputation by surgeons has been strongly considered. Individuals with BIID often feel desperate, and if this frustration continues it may lead to dangerous behaviors. These behaviors may include self-inflicted wounds, causing infection of these wounds, and burning a limb to injure it beyond repair in order to provoke amputation. Furthermore, these individuals may go as far as carrying out amputation on their own if a surgeon will not do it. Between 1997 and 1999, elective amputations were allowed in the United Kingdom in order to avoid these hazardous behaviors of individuals with BIID. However, such operations were quickly banned after they caught the attention of the public (Sorene et al., 2006). In order to minimize the harm that these individuals may inflict on themselves, amputation of healthy limbs by competent surgeons may be a viable option.

Another argument for the amputation of healthy limbs would be that an individual has the right to alter one's body in the pursuit of acceptance and happiness (Jotkowitz & Zivotofsky, 2009). Similar to those who undergo cosmetic surgery, as well as those who have had surgery due to Gender Identity Disorder, individuals with BIID are unsatisfied with their physical appearance and desire a change. Although both cosmetic surgery and GID surgery also encounter many arguments against altering one's appearance or gender, they are nationally recognized as an accepted medical practice. If

these types of surgery are allowed to improve one's body image, then elective amputations may not be far-removed from these common practices.

A final argument for the amputation of healthy limbs is the possible therapeutic effects that may occur post-surgery. Bayne and Levy (2005) describe this argument in four stages: (1) the individual suffers because of their condition; (2) amputation is expected to provide relief from this suffering; (3) less-serious approaches and treatments will not bring about this relief; and (4) the severity of amputation is minimal compared to finding relief of this disorder. Some individuals who are afflicted with BIID have stated that their condition has interfered with their social lives (Bayne & Levy, 2005), including their jobs and leisure activities. These individuals do have valid emotions and are truly suffering from an internal crisis, so regardless of the diagnosis of BIID, psychological intervention is necessary. Also, seeing as some BIID individuals go to extreme measures in order to reach liberation from their unwanted limbs, the therapeutic effects may be reason enough to allow healthy limb amputations.

Arguments against Healthy Limb Amputation

Without question, the allowance of healthy limb amputations by surgeons would inevitably be met by resistant forces. Society is likely to lead these arguments with feelings of repugnance and disgust. In the case of individuals who have lost limbs from accidents or disease, the thought of amputating a fully functioning limb is appalling. Paddy Rossbach, the president of Amputation Coalition of America, stated that " It's very difficult for people who have been through what they consider to be a devastating life experience to understand why anybody would want to mutilate himself in <https://assignbuster.com/desire-to-be-disabled-body-integrity-identity-disorder/>

this way," (Henig, 2005). Others who suffered unwanted amputation often say that the existence of BIID diminishes what they have been going through emotionally. Desired amputation will meet public disdain, and those who have experienced unwanted amputation will undoubtedly be at the forefront.

An additional argument against healthy limb amputations is the life-threatening consequences of such operations. According to Müller (2009), the principle of nonmaleficence states that physicians should not perform amputations without medical necessity. Such amputations often have severe consequences besides causing the individual to be disabled, including infection, phantom pains, thrombosis, paralysis, and necrosis (Müller, 2009). Furthermore, such operations may not be successful at bringing about the desired relief. In some cases, desire for a new amputation of a previously accepted limb may follow the first operation (Hilti & Brugger, 2010). Amputation causes irreversible damage that may not heal properly, and if the operation is not justified based on life-saving measures, permission of such operations may never be accepted.

Possible Treatment: Vestibular Caloric Testing?

A final argument against healthy limb amputations is the possibility of vestibular caloric stimulation as a treatment option for BIID. Although the neurological cause of BIID is unknown, one speculation is the involvement of the right parietal lobe. Evidence of somatoparaphrenia, or the belief that part of one's own body is not their own, has been documented in cases of right parietal lobe stroke patients (Müller, 2009). Neuroscientists Vilayanur Ramachandran and Paul McGeoch suggested that the right parietal lobe may also be involved in BIID patients, with supportive evidence that most who

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desire amputation show a left-side preference, as well as an emotional rejection of their unwanted limb (Müller, 2009). The speculation that vestibular caloric stimulation (specifically left-ear cold water irrigation) may be a treatment option for BIID is based on its known temporary treatment of somatoparaphrenia. Benefits of caloric stimulation over amputation include less-expensive treatment, lack of side effects, and immediate results showing if the treatment is working or not (Ryan, 2009). Overall, a trial of vestibular caloric stimulation should be the first step in treatment of BIID, and a clinical audiologist would perform this type of testing. For this reason, knowledge of BIID and the expertise to deal with these types of patients is important for audiologists to understand. Although caloric testing has not been proven to relieve BIID patients of their suffering, and the effects on bodily awareness may disappear as soon as the caloric stimulation has stopped, it is a less drastic approach that has been speculated to be successful.

In Conclusion

The limited knowledge of BIID as a valid psychological condition, as well as causes and treatments, is a barrier to finding some sort of relief for these individuals. Whether or not elective amputation is the solution for patients with BIID, the drastic decision to remove one's limb forever should not be made until more is known regarding BIID. Regardless of the background and probable causes of this disorder, individuals are still suffering daily from the notion that a body part is not their own. Intervention is necessary for BIID patients, whether it be vestibular testing by an audiologist, or other therapeutic remedies. Physicians should perform a thorough diagnostic

evaluation when encountering a patient with BIID. Prior to causing irreversible damage to that individual's body, other treatment options and therapy should be researched.