Role of Sexuality in Body Integrity Identity Disorder (BIID): A Cross-Sectional Internet-Based Survey Study

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ABSTRACT

Background: Body integrity identity disorder (BIID)—a strong desire for amputation or paralysis—is often accompanied by feelings and cognitions of sexual arousal, although this sexual component has been largely neglected in the recent literature.

Aim: To examine the presence of BIID-related sexual arousal in subjects with BIID and explore clinical and demographic variables of subjects with BIID who do and do not possess this sexual arousal.

Methods: Eighty individuals with BIID responded to an internet-based survey we created. For all subjects, restoring identity was the primary motivation for preferred body modification. We collected data about respondents’ demographic, clinical, and sexual characteristics. Based on responses to questions about BIID-specific sexual desires, subjects were assigned to the group with BIID-related sexual feelings (S-BIID; n = 57) or the group without such feelings (NS-BIID; n = 23).

Outcomes: Differences in clinical, demographic, and sexual characteristics between S-BIID and NS-BIID groups.

Results: Of the respondents, 71.3% endorsed S-BIID. Subjects with S-BIID were significantly more often men, religious, and of a homosexual identity compared with the NS-BIID group. Subjects with S-BIID also significantly more often reported a change in localization and/or intensity of their BIID feelings over time. Furthermore, 66.7% of subjects with S-BIID reported S-BIID as an additional motivation for body modification. Seven of the 57 subjects with S-BIID achieved their preferred body modification through (self-)amputation, whereas none of the subjects with NS-BIID did.

Clinical Implications: BIID is a heterogeneous disorder in which subjects who self-reported comorbid sexual arousal more often resorted to (self-induced) amputation.

Strengths and Limitations: This study contains the largest BIID cohort presented in the literature and is the first to genuinely research sexuality in BIID. The first limitation is the lack of face-to-face interviews with the subjects, so no clinical diagnoses could be made. Moreover, there is an ascertainment bias because subjects were collected through the internet and in English, which excluded those who spoke other languages or subjects without an internet connection.

Conclusion: The present study provides preliminary evidence for a subpopulation or distinct group of individuals with BIID based on the presence of S-BIID. Blom RM, van der Wal SJ, Vulink NC, Denys D. Role of Sexuality in Body Integrity Identity Disorder (BIID): A Cross-Sectional Internet-Based Survey Study. J Sex Med 2017;XX:XXX–XXX.

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INTRODUCTION

Individuals with body integrity identity disorder (BIID; also referred to as xenomelia) experience an obsessive, lifelong desire for amputation or paralysis that leads to enormous distress and decreased quality of life.1,2 This desire for amputation is the result of an incongruence between one’s experienced and assigned body.1–3 Most individuals with BIID report comorbid feelings and cognitions of sexual arousal associated with this
an identity disorder (ie, BIID). Recently, several magnetic resonance imaging studies on BIID have hypothesized abnormalities in the frontoparietal (body ownership) network that are related to the feeling of over-completeness with four limbs. These recent studies have focused on the neurobiological background of the disorder, and the identity and sexual components of BIID have been disregarded.

In questionnaires, individuals with BIID report a high prevalence of sexual arousal when they imagine being disabled themselves (44%–72%) or when seeing others with physical impairments (46.3%–87%). This sexual arousal is rarely seen as the main motivation for body modification (ie, amputation or paralysis; 0%–30%), although many subjects do report it as a secondary reason (30%–65%). De Preester was the first to genuinely study sexuality in BIID. She reanalyzed the data of a published descriptive BIID study and concluded that any form of sexual arousal related to BIID was present in almost 90% of subjects with BIID. Thus, sexual arousal appears to be a prerequisite for BIID rather than a coincidence.

Although these reported findings suggest that sexual arousal could be an important component of BIID, no study has examined the differences between individuals with and without this arousal. The objective of the present study was to inquire into the feelings of sexual arousal that accompany BIID, as presented in a large sample of individuals self-identified as having BIID, to try and identify subgroups with characteristic clinical and demographic features. Based on prior research, we hypothesized that a small subsample of subjects with BIID would not experience any BIID-related sexual feelings and would clinically differ from those subjects with manifest sexual feelings.

**METHODS**

**Sample Selection**

This study was part of a larger BIID questionnaire study. Subjects who identified themselves as having BIID (ie, recognizing themselves in the following sentence: “BIID is a term that covers several conditions in which people feel their body image does not match with their body shape. When we use the term ‘BIID’ here we mean to indicate all these different forms of the condition. For example, some people would like to have their leg amputated under their knee, whereas others prefer to resemble someone who is paralyzed.”) were recruited from December 2010 through February 2015 through BIID-related forums and websites or were referred to us by individuals who had already participated in the study. Because BIID is a rare disorder and individuals are often tremendously ashamed to share their complaints, all initial communication occurred on the internet and subjects were allowed to remain anonymous. No identifiable personal data (name, date of birth, and address) were obtained other than the participants’ e-mail address. Individuals who e-mailed to express interest in the study were given detailed participation information about the study by e-mail. After subjects e-mailed their consent to participate in the survey, an invitation to visit a secured website for the questionnaire was sent. In total, 93 individuals expressed interest, of which 90 (96.8%) completed the questionnaire. No data were available for the remaining three individuals.

The study was conducted in accordance with the code of ethics of the World Medical Association (Declaration of Helsinki) and approved by the medical ethical committee of the Academic Medical Center of the University of Amsterdam (Amsterdam, The Netherlands).

BIID is not officially listed as a diagnosis in the International Classification of Diseases, Tenth Revision or the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, although it does appear in the differential diagnosis of gender dysphoria or body dysmorphic disorder. Therefore, no official BIID criteria were available. Within the current literature, most studies on BIID use the criteria proposed by First: “There is a persistent desire to be disabled that causes significant distress, there is absence of psychosis. The primary reason for desiring to be disabled is to restore body identity. It reflects the individual’s feeling that having an amputation would correct a mismatch between the person’s anatomy and his or her sense of ‘true’ self (identity). The desire is not primarily motivated by sexual arousal or by any perceived advantages of becoming disabled.” To exclude fake or inappropriate responses, all results were checked and read manually. Especially reading responses to open narratives such as “How would you describe your BIID?” helped us to distinguish BIID from other conditions. We did not find any inappropriate responses, although for 10 subjects who completed the questionnaire, restoring body identity was not the main reason for body modification. Therefore, these 10 subjects were not classified as having BIID and were excluded from the analysis. Four subjects indicated “feeling sexually aroused” as the main motivation, another four subjects mentioned “the attention it draws,” and the last two subjects specified “the process of modification.”

**Measurements**

This study used the BIID Phenomenology Questionnaire. This questionnaire was developed in 2010 to obtain a detailed description of subjects with BIID and includes epidemiologic,
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