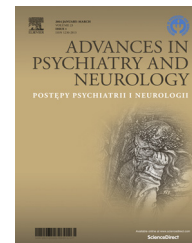


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Review/ Praca poglądowa

The rest is not me. . . An attempt to explain xenomelia – Neurodevelopmental hypothesis



A reszta to już nie ja. . . Próba wyjaśnienia xenomelii – hipoteza neurorozwojowa

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ABSTRACT

Aim: Article introduces xenomelia – a disorder of bodily experience that manifests itself in the feeling of disownership related to one of the limbs that a patient wants to remove. For a dozen of years, xenomelia has been investigated by psychiatrists and neurologists; yet, there is no agreement on its medical definition or diagnostic criteria. Recently, it has been proposed that apart from neuroanatomical factors that contribute to bodily awareness, social factors may determine xenomelia as well. In the paper, we investigate a social neuroscience view in developmental perspective. **Perspective:** We believe that the neurodevelopmental approach is the one that presents xenomelia in the most complex way. We propose to examine changes in bodily experiences related to social events that emerge during periods sensitive to development of multimodal neuronal representations of the body. We indicate that crucial changes occur in the adolescence, when social environment seems to have extremely powerful impact on self-consciousness and self-esteem. **Conclusions:** We demonstrate that xenomelia is a disorder of multifactorial aetiology. In order to explain it, we need to investigate social influence on the development of self-consciousness (and bodily consciousness). We highlight the periods that in our view are critical for the development of one's own body representations. We point to the neuronal representations related to self that undergo major changes during adolescence as we believe they have great impact on shaping bodily consciousness. We also believe that further investigations on neural body maps in infants may tell us more about the possible factors that affect xenomelia.

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Introduction

Xenomelia (from Greek: 'xeno' – foreign, 'melos' – limb) is a disorder of bodily consciousness manifesting itself as a patient's desire to have their limb amputated (most frequently the lower one), as the patient experiences it as excessive and thus foreign. The disorder has recently become the subject of research interest in psychiatry and neuroscience, and there is still no agreement among scientists concerning its nature. For this reason, xenomelia is listed neither in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) nor in the classification of mental disorders of American Psychiatric Association (DSM-V). There is also discussion in the medical literature whether xenomelia should be considered a psychological or a neurological disorder [1]. The term *xenomelia* has only recently come into use in the literature [2]. The condition was earlier referred to either as Body Identity Integrity Disorder (BIID) or apotemnophilia [3].¹ Since it is difficult to establish which diagnostic category would be most apt to convey the nature of this disorder [4], the term *xenomelia* has come to be widely used in literature for some time now [5]. It is used as a descriptive term, accentuating the patient's feeling that their limb(s) is not their own, while at the same time it does not determine the nature of such a state [5].

The disorder currently referred to as *xenomelia* was first mentioned in the medical literature in 1785 [6], while the first systematic research was initiated in 2005 by Michael First, who conducted interviews with 52 persons declaring their desire for limb(s) amputation [7]. Another study, with the participation of 20 persons diagnosed with xenomelia, was conducted by Olaf Blanke and his colleagues in 2009 [8]. In 2000, BBC aired a documentary titled *Complete Obsession*, raising the awareness of xenomelia among non-specialists. Despite the fact that so far a comprehensive scientific study on xenomelia has not appeared, certain criteria that characterise this unusual disorder have been proposed. According to First [7] and Obernolte et al. [9], xenomelia is rooted in early childhood and entails serious psychological distress (which frequently leads to attempts at self-amputation). Among population affected by xenomelia we can also observe an admiration for bodies of disabled persons, the attitude not shared with the rest of the society. Xenomelia affects mostly men² [7, 9]. Christopher Ryan holds that the key factor distinguishing this disorder is a long-standing and persistent desire for limb amputation, the desire which is the source of significant distress and which negatively affects the patient's social and professional life [10]. Persons affected by this disorder are convinced that amputation would allow them to regain their true identity. At the same time, other disorders such as somatoparaphrenia, psychotic

disorders or dysmorphophobia fail to offer a better explanation of the symptoms described above [10].

Xenomelia sufferers describe their experience in a surprising way (see: the Attachment). They claim that the limb they desire to have amputated does not constitute an integral part of their body. They are able to indicate the exact "demarcation line" where their "true" body ends [11, 12]. They perceive the part whose amputation they desire as the one that is excessive and unnecessary. Peter Brugger likens this state to a phantom limb experience and claims that we are dealing here with "negative phantoms" [13]. In the case of phantom limbs, the person feels the presence of the amputated limb. The patient can see that the phantom limb (for example the right arm) is in fact absent, but still feels its presence (mainly in a proprioceptive way). In xenomelia sufferers, we can observe changes in experience that may be interpreted as an experience of (proprioceptive) absence of the limb that constitutes a part of their physical body and which the patient visually perceives as such.³ We consider this parallel to be particularly valuable and believe that it allows better understanding of xenomelia sufferers. Even though the patients do not feel that the limb belongs to their body, they are still aware of its presence and they are forced to deal with it. Such a state can be the source of discomfort and frustration and it may finally become one of the factors triggering amputation. The sources of such a negative phantom require explanation. It seems that they may be linked to neurodevelopmental disorders in the regions related to multimodal representations of the body. These representations are shaped, to a large degree, by social experiences, especially in childhood and adolescence. Although at this stage of research it is impossible to conclusively identify the factors that cause xenomelia, we hope that the studies presented in this paper may prove a valuable starting point in the search for answers.

Sources and mechanisms of xenomelia

Xenomelia is most commonly considered a disorder of bodily consciousness (or body image), manifesting itself in distorted experience, feelings and beliefs concerning one's body [14].⁴ Assuming that our bodily consciousness relies on certain (neuro)physiological processes [15], we may conclude that in the case of xenomelia, we are dealing with some kind of impairment of these processes. It is known that in xenomelia the anomalies in cortical mechanisms are more frequently observed than the anomalies in the subcortical mechanisms [8]. These anomalies mainly occur in the parietal lobes [2], engaged in processing information concerning the state of the body and originating from various modalities. It has been suggested that the unwanted part of the limb is not included in the general representation of the body [13].

¹ We present a more detailed analysis of the differences between xenomelia and other disorders mentioned here in the final part of this paper.

² In the studies conducted by First [7] and Blanke et al. [8], women represented respectively 7% and 15% of the participants.

³ However, this state should not be reduced to ordinary loss of sensation. In those excessive limbs feeling – although somewhat changed (which will be described later) – is retained [12].

⁴ It is difficult to conclusively determine whether significant changes in xenomelia sufferers occur at the level of experience or are mainly related to their beliefs concerning their bodies [12].

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