



Commentary

Deepening the desire for disability: A commentary on Saetta et al. (2022)

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1. Introduction

Contemporary scientific research investigates the embodied nature of selfhood (Fuchs, 2020; Kiverstein, 2016; Rowlands, 2020). Scholars from different disciplinary fields describe bodily awareness as a pre-reflective phenomenon that relies on multisensory integration and extends beyond intra-body domains (Ehrsson, 2020; Gallese & Cuccio, 2014; Panagiotopoulou et al., 2017; Tsakiris, 2017).

Despite the complexity of the processes involved, the bodily self is ordinarily experienced as an integrated subjective whole. The nervous system plays a key role in mediating this kind of ‘immediacy’ (Fiorini et al., 2021; Fuchs, 2017; Stevenson et al., 2014).

Body Integrity Dysphoria (BID) is a peculiar condition characterized by a sense of personal disaffection with the presence or function of a specific body part (First, 2005). People with BID do not have brain damage, physical impairment, or psychotic symptoms; however, they report feeling a mismatch between their physical body and their self-perceived corporeality (Blom et al., 2012; Brugger et al., 2013). As such, these individuals may desire amputation of limbs (especially legs), motor inhibition (paraplegia/quadruplegia), and/or sensory deprivation (blindness, deafness).

Recently included in the ICD-11,¹ the label of BID brings together the different forms of desire, which share several experiential features. These include exposure to disabled individuals during childhood, sexual arousal toward physically disabled people, disability simulation behaviors,

disability-related obsessive thoughts, self-damages (Brugger et al., 2016).

The most common form of BID involves amputation of the left leg. In the neuroscientific field, some authors have accounted for this evidence by using the label of Xenomelia (foreign limb) to qualify stump desire (McGeoch, et al., 2011). This prevalence is widely described in the scientific literature, and, over time, the lateralization of desire has led to the hypothesis of a neurological origin of BID, primarily attributable to right superior parietal lobe (rSPL) dysfunction (Brang et al., 2008). In recent years, neuroimaging studies on amputation desire have shown structural and functional alterations in cortical and subcortical areas known to be involved in body image (Gandola et al., 2021; Hänggi, Bellwald & Brugger, 2016; Hilti et al., 2013; van Dijk, et al., 2013).

Saetta and colleagues (2022) work focuses on the most prevalent BID variant, comparing a control group of 16 healthy people with a group of 16 individuals with leg amputation desire. Although the sample may seem small, it is actually substantial given the rarity of the BID. Especially considering that the authors only included participants with an exclusive desire for left leg amputation.

2. Craving for disability

The sample size, along with the experimental design and methods used, make the study by Saetta and colleagues (2022) an essential landmark in the understanding of BID. A previous work by the authors had already identified structural and

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¹ <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/256572629>.

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functional gray matter abnormalities in individuals with BID (Saetta et al., 2020). This new study extends these findings by investigating the hypothesis of abnormal white matter structural connectivity in people with left leg amputation desire. Studies on possible alterations of white matter are crucial for understanding the physiological nature of the symptomatic manifestations of such a complex clinical condition (Hänggi et al., 2017).

The main findings of the study by Saetta and colleagues (2022) on the BID group can be summarized as following: 1) *hypoconnectivity* of the parieto-occipital network, which is probably responsible for the mismatch between the physical body and the body image; 2) *hypoconnectivity* of the cortico-striatal pathway, which is associated with erotic attraction to amputated bodies and reward-related behaviors; 3) *hypoconnectivity* of the left uncinate fasciculus, which is related to hyper-identification with amputated bodies and empathic responsivity; 4) *hyperconnectivity* between the right paracentral lobule (rPCL) and the right caudate nucleus, consistently related to obsessive-compulsive traits, clearly present in this rare condition (Braam et al., 2006; Blom et al., 2012).

These findings provide a broader picture of the neurobiology of BID, defined by Saetta and colleagues (2022) as a “network disorder”. The authors discuss the altered patterns of white matter structural connectivity found in their study by conceptualizing them with various experiential and phenomenological aspects that characterize the existence of people with BID.

In particular, the neurobiological evidence of visual processing involvement is quite new and fascinating (Oddo et al., 2018). Saetta and colleagues (2022) comment on abnormalities between the rSPL and occipital regions by hypothesizing a mismatch between the body image and the visually perceived body. The authors describe the temporary relief that undesired limb foreclosure from vision provides to people with BID during disability simulation or augmented reality settings (Turbyne et al., 2021). However, it appears that, in the long term, the simulation of disability amplifies the intensity and urgency of desire, as well as producing alterations closely related to the inhibition of limbs (Giummarra et al., 2011; Storm & Weiss, 2003).

Common to all forms of BID is the pervasiveness of thoughts on bodily dissonance. These ruminations unfold from an ‘internal sense’ of non-coincidence with one’s bodily integrity, which turns into a pathological focus on the presence or functionality of body parts. Individuals with BID spend a lot of time imagining themselves in their desired bodily state and the personal or social implications of becoming a person with a disability (Grochowski et al., 2018). Not surprisingly, BID has been compared to the *obsessive-compulsive disorder* (OCD), where persistent thoughts about disability are described as obsessions and simulation behaviors as compulsions (Braam et al., 2006; Blom et al., 2012). Some scholars have also investigated whether BID may be considered a body-related subtype of OCD (Link & Kasten, 2015). Interestingly, patients with OCD show alterations in the cortico-striatal pathway, the same altered striatal–orbitofrontal cortex connections (Jung et al., 2013) found by Saetta and colleagues (2022) in people with BID. These networks are known to be part of reward circuitry.

Previously, Oddo et al. (2009) hypothesized the involvement of the reward system in BID by describing the strong positive feelings that these individuals experience at the sight of people with disabilities and by simulating or imagining their disability. More recently, an fMRI study showed abnormal activity of the caudate nucleus when people with BID look at pictures of their own virtually amputated bodies (Oddo et al., 2018).

Oddo et al. (2009) also hypothesized abnormalities in dopamine release in people with amputation desire; if so, it could be speculated that simulating disability might increase desire. Some people with BID report that although body dysphoria is somehow always present in the “background”, the pressure with which it manifests is subject to what are termed “waves” (Pennisi & Capodici, 2021). One might wonder if these fluctuations in the intensity of body dysphoria might depend on hyper- and hypo-dopaminergic cyclic processes, as it occurs in *Bipolar Disorder* (Ashok et al., 2017).

Simulation of disability becomes one of the privileged ways to alleviate perceived dysphoria. These behaviors often begin very early in childhood, in the form of a game to be played in secret. While some people with BID do not perform simulations, others do so recurrently throughout their lives to the point that neuroplastic processes cannot be excluded (Brugger et al., 2013; Giummarra et al., 2011; Hänggi, Bellwald & Brugger, 2016). As already mentioned, those who simulate disability report feelings of relief during simulation moments, not experiencing the unwanted part. Moreover, for some of them, the simulation of disability is accompanied, over time, by a sexual component (Lawrence, 2009; Noll & Kasten, 2014). Finally, some people with BID report that they stopped simulating disability because the need to enact these behaviors – along with intrusive and recurring thoughts – was gradually becoming an impediment in daily life: «It slows the episodes but when I stop pretending, they get worse. It’s like a drug addict who gets a huge hit of heroin ... for a few minutes, all is perfect until the high wears off and the need comes back twofold» (Pennisi & Capodici, 2021, p. 233). Not by chance, in Saetta and colleagues (2022), alterations also emerge in the inferior frontal gyrus (IFG), which appears to be part of a behavioral inhibitory mechanism exerted on the ventral striatum (Shephard et al., 2020).

Neuroscientific studies show that the reward system relies not only on the cortico-striatal circuit but also on interoceptive mechanisms responsible to maintain physiological balance (Paulus, 2007; Walter et al., 2020). The insula plays a crucial role in processing bodily visceral signals and contributing to the maintenance of homeostasis (Craig, 2009; Critchley & Garfinkel, 2017). Alterations in this area are recurrently observed in psychopathological conditions that undermine basic bodily self-awareness (Ciaunica et al., 2021; Tsakiris & De Preester, 2018), in eating disorders (Vicario, Salehinejad, et al., 2020; 2020b), and addiction disorders (Paulus & Stewart, 2014; Vicario, Nitsche, et al., 2020).

Neuroimaging research on BID also show structural and functional alterations of the insula (Hänggi, et al., 2017; Hilti et al., 2013; Van Dijk et al., 2013), but few studies (Bottini et al., 2015; Brang et al., 2008) have addressed functions related to this area, such as disgust (Vicario et al., 2017). The study by Bottini et al. (2015) focused on the hypothesis of

emotional impairments in BID, showing that the only difference in these individuals is a reduced disgust response to violations of the body envelope. This has led the authors to hypothesize that repeated, voluntary exposure to amputated bodies throughout life may attenuate the disgust response in people with BID. However, the results of this study are not generalizable. Since interoception is a core process of body awareness, further studies in this direction would be of great interest in BID research.

3. The mismatch between mentalized body and physical body

Multisensory integration – especially the centrality of interoception in these processes (Seth & Tsakiris, 2018) – is nowadays a fundamental line of research that crosses several disciplinary domains. In the philosophical field, the Embodied Cognition approach has prompted reflection on the biological nature of the mind, describing the anticipatory feature of sensorimotor agents to predict risks and environmental circumstances that could compromise their survival (Di Paolo et al., 2017; Fuchs, 2017). Recently, computational neuroscience has also embraced these theories, giving rise to new frameworks of theoretical and experimental research. In a nutshell, the Predictive Processing paradigm (Friston, 2005; Seth & Friston, 2016) illustrates a Bayesian and hierarchical model of information processing. From this perspective, the brain generates probabilistic inferences about upcoming states of the body and the world, minimizing prediction errors of subsequent perceptions, cognition, and actions on the basis of prior experiences and statistical regularities (Seth et al., 2012).

The recursive loops of predictions and error signals during the integration of interoceptive and exteroceptive processes contribute to the stability and plasticity of the bodily self (Tsakiris, 2017). The theory of Predictive Processing finds continuity in recent studies related to both primary sensory processes and higher-level cognitive processes (Ficco et al., 2021; Fiorini et al., 2021), as well as the experience of body ownership (Seth, 2013) and body representations (Riva & Gaudio, 2018).

Given these premises, which are certainly not exhaustive, it is possible to return to the main findings of the study by Saetta and colleagues (2022), who hypothesize that the amputation variant may result from abnormalities of visual and sensorimotor processing. According to the authors, these alterations would unravel a mismatch between the body image represented in rSPL and the visually perceived fully-limbed body. Hence, returning to predictive processing, it is possible to hypothesize that the brains of people with BID, not anticipating the presence of the lower limb, are ‘surprised’ to see the leg (and its movement). A recent meta-analysis on the neural mechanisms of predictive processing (Ficco et al., 2021) reveals a large predictive network involving many areas found to be altered in the study by Saetta and colleagues (2022) and other studies (Hänggi et al., 2017; Hilti et al., 2013). Although the constant presence of the unwanted leg throughout life should correct predictions, it could be supposed that the functional disconnection found by Saetta and colleagues (2022) between rSPL and occipital areas could compromise

the multisensory integration mechanism and elicit body dysphoria at the phenomenal level, as if the physical leg is always a novelty for the brain. Thus, consistent with the description of Saetta and colleagues (2022), disability simulation behaviors would help minimize prediction error signals.

Saetta and colleagues (2022) also hypothesize that hyperconnectivity between rPCL and caudate nucleus may develop into obsessive symptomatology. Pathological attention may in turn affect multisensory integration processes (Donohue et al., 2015; Talsma et al., 2010; Talsma & Woldorff, 2005), increasing experiential discrepancy in people with BID (Capodici, 2020). A possible role of attention is also suggested by the recent study of Salvato et al. (2022) finding anomalous responses in the bilateral thermoregulation of lower limbs in BID compared with controls, during attention unilaterally directed to either leg.

4. Continuity and discontinuity between BID variants

Once again, the study by Saetta and colleagues (2022) highlights the multifaceted nature of this rare condition. In just a few years, scientific research on BID has become increasingly refined and widespread, thanks to the possibilities provided by the Internet, which has made it possible to build networks of information and contacts (Berger et al., 2005; Davis, 2012). These new interactive spaces allowed researchers to relate to BID communities and organize more rigorous settings and investigations. However, it remains challenging to recruit only individuals who desire a specific disability in protocols that require physical presence, as in the study by Saetta and colleagues (2022).

The authors’ study focuses on individuals with an exclusive desire for left leg amputation, offering considerable evidence on the most prevalent BID variant. This experimental option certainly raises interesting insights for future studies. For example, what results might be observed by subjecting people with paralysis desire to the same setting? As already mentioned, the ICD-11 classification also includes other forms of BID, which share with the amputation variant a strong sense of inadequacy toward the integrity of the body and many features of the lived experience. While it is not possible to compile an overview of brain evidence for BID forms that target paralysis and sensory deprivation, recurrent structural and functional correlates can now be traced for amputation desire (Fornaro, Patrikelis & Lucci, 2020). Here, it is not possible to dwell on the desire that involves sensory deprivation; however, comparing the amputation and paralysis variants may be interesting to understand whether these two forms of BID share the same neurobiological patterns or are different in nature.

The scientific literature shows that unilateral leg amputation is the predominant desire in male subjects. On the other hand, it seems that in the female population the most frequent desires are bilateral amputation or paralysis (Giummarra et al., 2012). This preliminary data has led to hypothesize sex-related differences in body representations (Giummarra et al., 2011). However, more research is needed to confirm these trends.

Some authors have argued that it cannot be excluded that the specific form of desire can also be influenced by cognitive instances (Kasten, 2019). It has been hypothesized that the desire for paralysis, if not a variant per se, may arise unconsciously as a ‘softer’ alternative to amputation (Blom et al., 2012). In the absence of substantial psychiatric and social differences between people with amputation desire and those with paralysis desire, Blom et al. (2012) considered these forms to be variants of the same condition. But is that necessarily so?

The subjective accounts of people with the two forms of desire differ somewhat. Returning to the beginning of this brief commentary, the bodily opacity experienced in the amputation desire relates to the physical presence of the limb. Saetta and colleagues (2022) discuss this perceived structural excess through the mismatch between the body image and the visually perceived body. Individuals with amputation desire describe feeling the inner edges of the stump, an internal sensation of the optimal cut height (Freedberg & Pennisi, 2020; Pennisi, 2021). Instead, what seems to disrupt bodily transparency in the desire for paralysis is not the presence but the functionality of the body (Capodici, 2020).

Because of the wide range of disorders that affect body awareness, the existence of multiple mental representations of the body has been hypothesized (Moseley et al., 2012; Riva, 2018). Philosophers, psychologists, and neuroscientists have focused primarily on body schema and body image, discussing their experiential properties and neural correlates (De Preester, 2021; Ho & Lenggenhager, 2021). Although these dimensions are highly interrelated and not easy to isolate (Irvine et al., 2019; Pitron et al., 2018), maintaining this distinction may be helpful for theoretical and clinical purposes (Gallagher, 2001). Where body image is variously considered to be related to the perceptual, conceptual, and emotional dimensions of the bodily self, body schema is traditionally understood as a sensorimotor and action-oriented process (de Vignemont, 2010; Gallagher, 2005; Merleau-Ponty, 1945). From a phenomenological perspective, the variant of paralysis appears to involve a disturbance in the processes of monitoring and execution of movements. Something that seems to be more about the body schema than the body image: «My personal theory is that there is a neurological explanation, at least in part. I believe that there is occasionally a problem with feedback loops in my brain that govern movement initiation in my lower body. Perhaps when I am experiencing symptoms, there is a lag in communication between the parts of my brain that control movement intention and those that process whether the movement has been successfully executed» (Pennisi & Capodici, 2021). Is it possible that the desire for paralysis may involve prediction error signals related primarily to the motor processing? Further studies of the neurobiology of paralysis desire could shed light on the unresolved question of the nature of this variant. Is it the same network disorder (mentalized in the paralysis format) investigated by Saetta and colleagues (2022), or is it another condition involving different brain abnormalities while presenting experiential continuities with amputation desire? To date, Salvato and colleagues’ study (2022) may suggest a common neurobiological substrate between the two variants, showing an indistinct bilateral skin temperature decrease in lower limbs in people with amputation desire for the left leg.

While it is true that ICD-11, researchers, and people with BID themselves perceive the different forms of desire as different manifestations of the same condition (Patrone, 2009), future experimental studies on the other BID variants could also be useful for treatment purposes. By offering a solid evidence base for the most prevalent BID variant, the study by Saetta and colleagues (2022) could provide a starting point for further investigation and comparison, although difficulties in sample recruitment remain. In addition, although research on amputation desire has made significant progress over the past decade, much more investigation will be needed to understand the complexity of this condition.

5. Conclusions

Saetta and colleagues’ study (2022) offers many insights that cannot be explored in this commentary, including the sexual arousal that permeates disability desire. Or the observation that many altered brain areas (i.e. IIFG, IMTG) in Saetta and colleagues’ study (2022) are also involved in semantic and linguistic processes of bodily self-consciousness (D’Argembeau et al., 2014; Owens et al., 2010; Thompson-Schill et al., 1997). Moreover, neuroscientific research shows that the dynamics of expectation and novelty discussed in the previous paragraphs are not exclusive to intracorporeal processes but also intercorporeal processes. Recent studies show that viewing amputees produces a significant resonance in the action-observation network (AON) in healthy people, even more than viewing an ordinary body, especially in more empathetic individuals (Liew, Sheng, & Aziz-Zadeh, 2013). Repeated exposure to amputee bodies has been shown to reduce activation of the AON, except in the occipital cortex and SPL (Liew, Sheng, Margetis, & Aziz-Zadeh, 2013). This research is consistent with the hyper-empathy hypothesis within BID studies, which does not rule out that encounters with disability may trigger an intense emotional response in individuals with BID, leading to the integration of the other’s corporeality into one’s body mentalization processes (Aoyama et al., 2012). The alterations in visual processing and mirror system areas found in Saetta and colleagues’ study (2022) seem to confirm what has already been stated by several neuroscientists (Brugger et al., 2013; Sedda & Bottini, 2014), namely that *Body Integrity Dysphoria* is a complex phenomenon in which neurobiological, psychological, and social processes are involved.

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