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Bodies that love themselves and bodies that hate themselves:

The role of lived experience in Body Integrity Dysphoria

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1. Introduction

Ordinarily, each of us experiences the primary and implicit *sense of body ownership*, a belongingness that accompanies every conscious experience. Our body is, as Sartre said, “passed by in silence” (Sartre, 1943, tr. 1956: 330). Sometimes, however, this tacit harmony between body and mind can be problematic and emerge to consciousness and thematization. This discrepancy in bodily self may occur in neurological and psychopathological disorders; the scientific literature presents a variety of clinical cases in which subjects express feelings of estrangement towards their body as a whole or parts of it. In many of these disorders, there is a cognitive dissonance between the subject's body image and his body consciousness.

This work focus on the phenomenology of a condition in which subjects aspire to amputation or functional/sensory deprivation of a healthy body part. In most cases, the target of desire concerns the amputation of the lower limbs. However, this may also involve amputation of the upper limbs, paralysis or damage to the visual and auditory organs. People with BID are not typically affected by specific mental disorders, such as depression, paranoia, schizophrenia, neuroses. In this pathology, there is an alteration in the relationship between the imagined/narrated body and the real body. The specific desire for amputation, for example, involves that the ideal body denies the real body «until he wants to physically eliminate it, abolish it, kill it not metaphorically but *carnally*» (Freedberg and Pennisi, 2020: 16).

Most of these people claim that only amputation path will allow their body to match their body image (Kasten, 2009: 17). In this scenario, the argument of surgeries is still highly controversial (Bayne and Levy, 2005; Müller, 2009). Since professionals are not authorized to remove or inhibit healthy body parts, individuals with this disorder often go to extremely risky self-mutilation practices. To date, psychological therapies have rarely been effective (Thiel, Ehni, Oddo, and Stirn, 2011). In contrast, some people who have achieved the desired disability have reported an improvement in their quality of life (Smith, 2004), although in some cases the desire reappeared later focusing on other body parts (Sorene, Heras-Palou, and Burke, 2006; Berger, Lehrmann, Larson, Alverno, and Tsao, 2005).

Currently, the desire for disability is not present in the DSM-V, but it has been listed with the Body Integrity Dysphoria label (code 6C21) in the ICD-11, which will officially come into effect in January 2022. In line with this classification, in this paper we will adopt the last expression (BID) to highlight the first-person perspective of those who experience this disorder. In particular, we have conducted a qualitative study through a questionnaire that aims to bring out different aspects of the lived experience of these subjects.

2. The body as a target of love and hate

As mentioned above, BID variants imply a dissonance between the real body and the imagined one, i.e. the body constructed through internalized narratives.

In this regard, it is also possible to think about anorexia, vigorexia and body hacking (Pennisi, 2020). The gaze of these subjects immersed in their body reflected in the mirror can transform the anorexic body into an obese body, the body of a superpalestrate into a slender body, the fully tattooed body in someone who realizes that it is still possible to color his own sclera (eyeball tattoo).

One could hypothesize that under these dysphoric behaviors can be traced the will to improve one's body, to make it attractive to others. A mental mirror in which lies the universal biological principle of sexual selection. Even among non-human animal species, in fact, something very similar happens: peacock, under the pressure of natural selection, has developed a wonderful colorful tail adorned with showy shapes, but this anomalous genetic evolution has made him lose the ability to fly and sing. The same can be said of the superb antlers of the alpha-male moose that ended up damaging its ability to move in forests full of low branches.

One could continue to list a dense series of other “marvelous monstrosities” that have benefited sexual selection but, at the same time, have drastically limited other bodily possibilities of the more genetically showy subjects. Here it will suffice, however, to observe that among non-human animals the selection process takes place through gradual modifications of the body structure between generations without any contribution of a voluntary individual choice.

BID does not follow the same criteria of the bodies “who love themselves”. In these cases, the body image is always oriented towards the conservation and idealization of the body picture. It is the body that wants to love itself that produces conflicts. If we didn't love our body, we wouldn't take care of it, we wouldn't do anything to improve it, to adorn it, to keep it intact. It is sexual selection that naturally pushes us in this direction (Freedberg and Pennisi, 2020: 13).

On the other hand, there are also bodies that hate themselves. The *Misoplegia* (now *Somatoparaphrenia*), e.g., described by Critchley in 1955 is a condition in which patients with hemiplegia refer disdain or even hatred for paralyzed limbs. Misoplegics verbally attack their diseased limb and often strike it with their hands or with an object. In this pathology, neurocerebral alterations cause a failure in the sense of belonging of limbs: somatoparaphrenics can attribute their arm to others or demand its removal; they can insult and hate the part or pamper it to convince it to die (Loetscher et al., 2006). However, «the misoplegic has serious reasons to hate his body: there are no “mystifications” of this body, they are not mental images generated exclusively by ruminations or inner narratives», but a neurocerebral alteration that causes a lack of bodily consonance (Freedberg and Pennisi, 2020: 13).

Pennisi (2020) reports a second dimension of bodies that hate themselves; these cases concern apparently healthy bodies, whose dysphoric condition is attributable to a discrepancy between the body and its image, a disharmony that inevitably generates psychic and social repercussions.

In previous studies (Pennisi, 2020; Freedberg and Pennisi, 2020), it has been pointed out that body image disorders result from an altered complex system involving biological and psychosocial factors, including cultural and social customs, libidinal pressures, sexual repression. Unlike self-loving bodies – which adapt and modify (through food, training, resistance to pain) while always remaining themselves – self-hating bodies are immersed in an inexorable path that can only end up making them different from how they were born.

The suicides that occur in the population with *Gender Dysphoria* (GID) make it clear how unsustainable it can become to survive these unbridgeable bodily dissonances. According to data surveyed by the National Transgender Discrimination Survey (NTDS) and published in September 2019 (UCLA) in the US as many as 80% of them have seriously thought about suicide while 42% among MTF (male-to-female) and 46% among FTM (female-to-male) actually attempted it. People with gender dysphoria commit suicide 10 times more than other people (4.5%).

Unlike anorexia and other “bodies that love themselves”, it is plausible to assume that in BID and GID there may be the involvement of organic processes and substrates, which favor the evolution of body identity.

3. Which approach in the field of BID studies?

The nomenclature used to refer to this condition has changed over time in line with the approaches adopted for its investigation (Sedda and Bottini, 2014). The first scientific report was proposed by Money (1977) with the label “apotemnophilia”, in which the investigation has focused primarily on the sexual and paraphilic components of desire.

Subsequently, both “Amputee Identity Disorder” (Furth and Smith, 2000) and “Body Integrity Identity Disorder” (First, 2005) labels attempted to highlight the hiatus that can occur between the anatomy and identity of these subjects, stressing that sexual arousal is not a primary motivation.

In the neuroscientific field, instead, McGeoch and colleagues (2011) proposed the term “Xenomelia” to qualify a congenital dysfunction of the right upper parietal lobule and its projections with the insula (Ramachandran and McGeoch, 2007; Brang, McGeoch and Ramachandran, 2008). This anomaly causes a decoupling between the body image in the right parietal lobe and the actual physical body. This discrepancy was detected by both Magnetoencephalography (MEG) and Skin Conductance Response (SCR).

As for the latter, Ramachandran and colleagues – starting from the observation that many subjects with BID report a specific cut height – conducted a SCR study by applying on each leg small electrical stimuli above and below the desired amputation line (on feet and thighs). Subjects who desired an amputation under the right knee exhibited a double difference in SCR between the left and right legs below the amputation line, another double difference through the desired amputation line on the right leg, but no observed difference in normal limb. In xenomelics who desired a double amputation both under the left knee and under the right thigh the differences recorded were greater: there was a triple difference below the amputation line compared to above in both the left and right legs. Of course, nothing similar occurred in the control subjects. According to the researchers, these results prove that Xenomelia derives from the congenital malfunction of the upper right parietal lobule, which receives and integrates inputs from various sensors in the areas and from the insula to form a coherent sense of body image.

Magnetoencephalography (MEG) studies have also gone in this direction, reinforcing cerebral hypothesis. McGeoch and colleagues (2009) showed an absence of activity in the upper right parietal lobe following tactile stimuli on the unwanted limb in subjects with BID. This implies that although individuals with BID can feel the target body parts, these may not be integrated into the body image, eliciting the desire for amputation.

In the scientific literature, it is possible to trace constant behaviors which seem to confer plausibility to brain-based hypothesis. Many of those who experience this condition are extremely convinced that there are no alternatives to the epilogue that involves body damages. Another aspect that could be mentioned is the disproportion between the amputation requests. Many subjects, indeed, aspire to left leg amputation, while fewer

subjects experience a desire focused on the right leg or both legs. Furthermore, a large number of subjects pose the onset of desire during childhood. These data seem to suggest an interference in neurodevelopment processes, which may have occurred, perhaps, during embryogenesis.

The Embodied Cognition approach aims to go beyond the brain considered in isolation, highlighting the role of the dynamic brain-body-environment relationship (Gallagher and Zahavi, 2008; Shapiro, 2011; Capodici and Russo, 2019; Capodici, 2019). Therefore, the purpose of this study is not to reject neuroscientific hypotheses, but to emphasize some recurrent aspects of the lived experience of these subjects that cannot be neglected. The idea is to move away from a purely reductionist view of this phenomenon, as already expressed by Brugger and colleagues (2013; 2014; 2018), who suggested that it is necessary to consider not only neurological factors but also psychological and social ones.

In the perspective of these researchers, for example, it is not possible to neglect the sexual component of the desire for disability, as the insula is not only involved in interoception but also plays an essential role in somatoesthetic and sexual arousal (Brugger, 2013). Furthermore, as we will see later, neurological theories cannot satisfy all the occurrences of the phenomenon: sometimes it happens that the target of desire can change from one leg to another (Kasten and Stirn, 2009), or that desire can re-emerge in other forms after a first amputation (Sorene et al., 2006). Moreover, Brugger and colleagues invite the scientific community to pay attention to the phenomenon of brain plasticity which, lasting over time during the development of each individual's life, could explain the connection between neurobiology, environment and socio-cultural influences (including those of telematic spaces).

Such an approach allows investigating aspects of BID that deserve more attention, such as – among others – exposure to amputees during childhood, pretending behavior and virtual places in which users meet to confront their experiences. Events and practices that imply the presence of other people, objects and a social environment. Therefore, the hypothesis is that experience can retroact and influence some of those processes involved in the onset and maintenance of BID.

4. The Self-narrative questionnaire

The study aims to investigate the first-person perspective of those living with the BID through a qualitative questionnaire in order to highlight different aspects of these lived experiences. The questionnaire consists of 6 sections: 5 of them propose three open-ended questions, while the last one is formulated as a closed-ended question (the items can be consulted in § Appendix 1, while the quantitative data extracted and distributed in tables are shown in § Appendix 2). The research has been authorized by the Ethics Committee of the Department of Cognitive, Psychological, Pedagogical and Cultural Studies of the University of Messina.

Participants were recruited through different web platforms (Reddit, Facebook, Tumblr). Initially, the study involved 69 participants, but we excluded three minors from the results. The youngest of them was 13 years old while, of the 66 remaining participants, the oldest is 75 years old. We divided the participants into three age groups, as can be seen in Table 1.

Our data about the provenance of the participants overlap with those already found in the literature. In Table 2, it is possible to see a distribution of participants by continent of origin. It seems that there is a prevalence of the phenomenon in Western cultures (Lawrence, 2009); however, these data may derive from more limited economic possibilities, from the

existence of specific networks linked to the country of origin or – as highlighted by Blom (2016) concerning Eastern cultures – from intrinsic cultural characteristics.

As shown in many other studies (Johnson et al., 2011; Blom et al., 2012), a substantial number of participants are male (43 subjects), 14 are female and the last 9 declared other dimensions of gender identity, such as non-binary (Table 3).

In general, the most desired form of disability (Table 4) is amputation (71.2%), followed by paralysis (15.2%) and sensory deprivation (7.6%). It was necessary to create the “mixed” category that includes 3 participants (4.5%) and which we will describe below. Lastly, a participant was placed in the category “Not better specified” (N.B.S.) because he did not indicate the form of his desire.

The most common form of disability (Table 5) among male subjects is leg amputation (37 participants), followed by paralysis (3 participants) and sensory deprivation (1 participant desires blindness). Two subjects reported a mixed desire: the first stated that he desires to become wheelchair dependent, regardless of the type of disability needed for this purpose. The second declared that he sometimes feels the desire to be a DAK amputee and sometimes to be a paraplegic.

Among female participants, the most common desire is for paralysis (6 participants), followed by amputation (5 participants) and sensory deprivation (2 participants desire blindness). It was not possible to trace the desire of 1 participant (N.B.S.). These data confirm the prevalence of desire for amputation in the male population and desire for paralysis in the female population (Brugger et al., 2016: 1176). In the latter case, however, our study shows a minimal gap between the desire for paralysis and the desire for amputation.

Finally, the most common desire in the “Other” category concerns amputation (5 participants), sensory deprivation (2 participants), paralysis (1 participant) and a mixed desire (1 participant) that concerns a leg and genitals. This participant has already reached eunuch condition. In literature, however, the inclusion of the desire for emasculation or castration in the BID spectrum is highly controversial (Wassersug et al., 2007; Lawrence, 2010; Johnson et al., 2010).

Some participants’ answers will be reported integrally in the next paragraphs, while an overview of the data can be found in §Appendix 2. However, this study has limitations, such as the fact that the sample recruited on the web has not been previously tested and differentiated. Besides, the quantitative data presented in this work emerges from the descriptive answers given by the participants to the open questions, so we have schematized the data to extract objective results. For this reason, these data are necessarily incomplete. When quantitative data could not be determined, we opted for the expression “Not better specified” (N.B.S.). Therefore, it will be necessary to integrate this research with other quantitative and experimental methods.

5. Growing with a growing desire

«At age 5 I knew. I remember it well. It is my strongest memory. I saw a one-legged woman on crutches. And I was nailed to the floor, unable to move, think or anything else. I was completely awestruck. I couldn't take my eyes off her. And when she left my eyesight I could act again” (*a participant's response to our questionnaire*).

In scientific literature, childhood-related stories are quite recurrent. In our study, in fact, 72.7% of the participants placed the onset of the disorder in childhood (Table 7).

This prevalence had already emerged from the two cases presented by Money (1977), both of which reported an early onset of the disorder. However, twenty years later, Bruno (1997) emphasized more prominently the role of exposure to the sight of amputees in childhood. He proposed the expression “Factitious disability disorder” to describe a desire

for disability ascribable to the emotional sphere, in which the lack of parental love and the envy felt towards caring for disabled people would translate into the desire to acquire disabilities and attentions related to it:

«My earliest memories are probably in 4th grade – which was a time of my life marked by big changes [...]. I felt ignored and “un-special,” so I began limping to see if anyone would notice. At the time, I had a brother who had an ankle brace so I thought I could garner enough attention for my parents to coddle me and take me to a doctor, where I would be thoroughly looked after. Over time, I guess, this desire for love and attention (hopefully I don't come across as narcissistic – I was just a lonely kid living in a chaotic situation) evolved into an obsessive search for ways to earn love and affection. People are much kinder to you when you are physically disabled» (*a participant's response to our questionnaire*).

However, many individuals with BID deny that a search for compassion drives their request for disability. Indeed, as pointed out by some authors, people with BID often idolize people who are successful in life despite their disability (Kasten, 2019: 33).

«I was terrified that [...] strangers would ridicule me or accuse me of being an attention seeker (even though attention to this aspect of my life was the absolute last thing I could ever want)” (*a participant's response to our questionnaire*).

Furthermore, from a study focused on the childhood of subjects with BID (Oberholte, Schnell, and Kasten, 2015), no significant evidence emerged relating to inadequate parental care, neither in terms of physical abuse nor as overprotective control. Therefore, the purpose of this paper is not to describe BID as a Factitious Disorder; nonetheless, we believe that Bruno's hypotheses are interesting above all for the attention paid to the emotional dimension.

Enactive theories emphasize *how we affect each other*, that is, how the encounters we make in the course of our lives contribute to the constitution of subjectivity: «social interactions not only modulate us, they partly make us into who we are” (De Jaegher, 2015: 125).

Oberholte and colleagues (2015) reported that subjects with BID tend to remember a higher number of experiences with disabled subjects, compared to the control group. In particular, BID sufferers vividly remind contacts with amputated or paralyzed people (and not, for example, with those affected by mental retardation). However, the authors specify that it is difficult to determine whether the subjects with BID were exposed more frequently to disabled subjects than the control group or if they remember these events better due to the continuous thematization around their own corporeality. In accordance with the key-lock principle, Oberholte and colleagues (2015) show that, since childhood, subjects with BID react with a positive attitude to the first sight of disabled subjects.

As already mentioned, it seems that for many subjects, early exposure to amputees represented a kind of trigger for the apprehension of the disorder. According to some authors, this interpretation seems to follow the concept of “maternal impression”, which correlates the pregnant woman's exposure to the sight of amputees to a high risk of giving birth to a child affected by congenital limb deficiencies (Aoyama, Krummenacher, Palla, Hilti, and Brugger, 2012: 106). Aoyama and colleagues specify that, although this theory is superstitious and childhood-related stories could be considered as retrospective reconstructions, it should not be excluded that an intense emotional experience may influence the representation of the body (*ibidem*).

Therefore, empathy could play a significant role. In this regard, a study has shown that visual exposure to the actions of an amputee influences our sensorimotor responses (Liew, Sheng, and Aziz-Zadeh, 2013). In more detail, Liew and colleagues wondered what

happens when we see a body in action that does not match to our body. In particular, they conducted an fMRI study on subjects with minimal experience with amputees, showing them short videos of an amputee woman (both arms above elbow) performing a series of actions with her residual limbs and videos of actions performed with the hands by a physically ordinary woman. Surprisingly, the observation of the amputee woman decreed a greater sensorimotor resonance in the AON (*action observation network*), particularly in the right inferior and superior parietal lobule, especially in the most empathic subjects (Liew et al., 2013: 144). A second fMRI session conducted after prolonged exposure to both video categories showed an attenuation of the difference in the AON in response to the residual limbs and hands, except in the right superior parietal lobe and occipitotemporal regions, suggesting the updating of the internal model of the participants. Although this experiment focuses on action view and motor response, it can provide interesting insights. First of all, it allows us not to exclude possibilities of incorporation of other's bodies into one's own body representations. Secondly, the evidence that empathic subjects could be more susceptible to this eventuality could strengthen some hypotheses already expressed in the context of the BID.

In particular, some authors mentioned that a hyperempathic response to the sight of an amputee might predispose subjects with BID to the integration of these bodily defects in their own representations of the body (Hilti, Hänggi, Vitacco, Kraemer, and Palla, 2013; Brugger, Christen, Jellestad, and Hänggi, 2016). The authors highlighted these aspects by describing the “mirror-touch synaesthesia” phenomenon, i.e. the experience of healthy subjects who, observing tactile stimulations on the body of others, feel the sensation of being touched. The interesting aspect is that this sensation also emerges on the phantom limb of amputees, although their physical body does not match with the observed one. Moreover, Hilti and Brugger (2010) considered the BID as a “negative phantom”, that is the counterpart of the *aplastic phantom limb*, in which subjects, observing the movement of others' limbs, perceive the presence of their absent limbs. Therefore, in BID «observing the absence of another person's limb could unmask a congenital underrepresentation of the person's own present limb» (Brugger et al., 2016: 1182).

Our questionnaire shows that the sight of amputees could be considered by subjects as trigger factor (at least for the apprehension of the disorder) even if the event did not occur in presence. In fact, some participants remember seeing amputees on TV or on the web during childhood or adolescence:

«I think it was when I watched this one episode of CSI or Law and order or one of those kinds of shows. A perpetrator took part of a limb from people when they came to him for a different type of surgery, I think. I was very young and I don't know if I had it at that moment because of it, or if it was in line with what I already “wanted/needed”. Like beforehand maybe it was a passive thought, and the episode made it a conscious thought” (*a participant's response to our questionnaire*).

Although the power of images over the body – with a particular mention to those that depict human bodies – represent a theoretical area that should be more investigated experimentally (Freedberg and Pennisi, 2020), it is difficult to conclude that the aetiology of BID can be reduced to the impact of the sight of disabled people. If this were the case, one could hypothesize the involvement of empathic factors that could reassemble the mirror neuron system's neural prerequisites and their effects on imitative activity.

This thesis has been strongly contested by Ramachandran in all the writings that we have reported previously, to the point of ridiculing it («others have proposed that seeing an amputee at a young age has caused this to be somehow ‘imprinted’ onto the sufferer's psyche as the ‘ideal body image’», Brang et al., 2008: 1305). Notwithstanding the fundamental disagreement, in another essay Ramachandran however resorts to a reconstructive

hypothesis involving mirror neurons in the origin of the formation of body self-awareness. The self is not for him a holistic property of the brain but a function of specific sets of interconnected brain circuits. Its main characteristic is recursion, that is, the property of turning within the self, of turning one's own attention to one's mental image.

The specific neurocerebral components on which this property would be based have their roots precisely in the mirror neurons which are highly concentrated in the lower parietal lobule of great apes and in humans. With the evolution of the brain in hominids, the lobule divided into two turns – the supramarginal gyrus and the angular gyrus. The first specialized in reflecting on the body pattern that allows to anticipate the actions necessary to avoid damage in the spatial movement. The second in the management of the body image and, probably, in the social and linguistic aspects of the left hemisphere of our cerebral self. Hence the emergence of self-awareness.

Of course, Ramachandran immediately takes precautions against the naive interpretations of this thesis by declaring that mirror neurons are not sufficient for the emergence of the self, otherwise the self-awareness of the other primates should also be supported. The recursive predisposition of mirror neurons is indeed intertwined in human animals with areas of language (in particular with the Wernicke's area that allows their understanding) and with part of the frontal lobes.

These hypotheses could represent an explanatory cue not only for the pathology but also for the physiology of body image and self-identification processes. The perspective that considers ontogenetic development, in fact, allows to conjugate biological aspects of the brain-body and those of the non-brain-body, and so psychological, cultural and social factors.

6. Enacting disability

In the scientific literature on BID, the simulation of disability is undoubtedly one of the most recurrent aspects. Traditionally, this practice is defined with the expression “pretending behavior”. However, when questioning subjects with BID on this issue, it becomes clear that this terminological choice is not unanimously appreciated:

«First of all, I'd like to argue that the word 'pretending' is not fully applicable (and potentially harmful) for our condition. Two reasons: first of all the media attention this disorder gets is usually of a sensational nature, which is in a way understandable. But if we are to get other people to be more accepting of BIID I think a different term would be better. This sketches an image of people using medical aid equipment 'for fun' or to 'get free handicapped parking spaces'. Unfortunately this also makes it easy to confuse BIID with medical fetishes. I know those two aren't mutually exclusive, but for the outside world this isn't so easy to understand».

«I actually feel very strongly that we should NOT use the word “pretending”. To me, the word “pretending” implies that the actions are make-believe, unnecessary, and/or deceitful. I think this is extremely harmful to those who are already living with a lot of shame from BIID and who are most likely struggling with the idea of ever being open and honest about their situation. I prefer to think about using various assistive devices or binding a limb, etc. as coping behaviours or management of the BIID discomfort. When both the community of researchers and people affected by BIID use the word “pretending”, in my opinion it sends the signal that these behaviors must be kept a secret (and that is not a healthy way to move forward). I have been trying to change the discourse within my community, but I also hope that perhaps you could amplify this request both to researchers studying BIID as well as to those struggling with it» (*a participant's response to our questionnaire*).

The study conducted by First (2005) showed that 92% of the participants practiced or had practiced the simulation of disability. Our data on disability simulation can be observed in Table 8: the “Yes” category shows that 63,6% of the participants currently practice simulation. This category also includes participants who have been amputated but who simulate further disabilities. The category “Not anymore” includes participants who stopped simulation practices (15,2%) due to the following reasons: frustration, futility, reinforcement of desire, the achievement of the desired disability. Furthermore, we chose to include the category “Not yet” (4.5%) which concerns participants who have explicitly stated their intention to engage in the simulation in the near future (as soon as conditions allow or when they can get the necessary devices). Finally, 9 participants (13,6%) stated that they had never practiced and for 2 participants (3%) it was not possible to determine the category (N.B.S.).

The disability simulation consists in mental images or motor actions related to the desired mode of existence, so the subjects try to inhibit the functionality and the presence of the unwanted body part, avoiding to involve it in the movement (Brugger et al., 2013: 3-4; Blom, Hennekam, and Denys, 2012). Often, even these practices start from childhood, as one of our participants described:

«I have had it for as long as I can remember, but the first time I remember thinking of it was when I was five and I found that I could pretend using a crutch. I remember thinking that I wasn't ment to walk and also I felt a need to hide that because I felt ashamed of what I felt, so I only “played” when I walked on crutches or used a wheelchair when no-one was watching.»

According to some authors, the (congenitally or developmentally) alterations of body representations in BID could be strengthened by mental images and simulation practices (Giummarra, Bradshaw, Nicholls, Hilti, and Brugger, 2011a: 327). By inhibiting the unwanted part, the remaining limbs assume the total load of motility. It has been hypothesized that this functional switch could lead to a reprogramming of the motor representation of the limbs, reducing the representation of the unwanted body part (Hänggi, Bellwald, and Brugger, 2016: 766). Langer and colleagues (2012) showed that immobilizing a limb for two weeks is enough to induce a rapid reorganization of the sensorimotor system and – through a motor imagery task – Meugnot and colleagues (2014) demonstrated that 24 hours of sensorimotor deprivation through hand immobilization can decree changes in its cognitive representation.

Regarding BID, the scientific literature presents some cases in which simulation behaviors led to alterations strictly related to limb inhibition. For example, Storm and Weiss (2003: 631) showed the case of a subject who, due to the persistent use of tourniquet, reported a sensory decrease to light touch and pinprick on the ankles, reduced vibratory sensitivity at the big toes, weakened ankle and plantar flexion and absent ankle reflexes. In relation to the role of lived experience, Giummarra and colleagues (2011b) discussed a more significant case, which shows how simulating a disability could culminate in the amplification of the desire itself. In particular, a subject with a desire for paralysis, accustomed to wearing steel orthoses, has developed (in addition to leg deterioration and atrophy) the desire to amputate both legs at the level corresponding to the top of the orthosis (Giummarra, Bradshaw, Hilti, and Nicholls, 2011b: 37).

However, although the simulation of disability appears to be a relief from a discomfort experienced since childhood, some authors point out that, over time, its palliative effect fades (Aner, Schmitt, and Kasten, 2018). In this regard, we asked our participants to describe what the simulation represents to them. Our question about the feelings aroused by the simulation included the words “frustration”, “palliative”, “relief”. In most cases, the subjects followed these categories to describe their experiences. Cases departing from these

categories were differentiated into “Relief and shame”, “Relief (but strengthens BID)”, “Fun” (Table 9). Our questionnaire, in sum, reports ambivalent feelings:

«[...] I used it for several reasons: 1) it did good and felt so good, it brought lust, 2) I needed to try how it is to use a wheelchair, 3) it seemed to lower the stress, the tension to some degree. But then I found that in the long run it increased the BID pressure, it made it more different to push my desires, fantasies, etc.»

«For me it's mostly a relief. For once, even though its just for a moment, I can feel more whole as a human being. But at the same time it might add frustration because in the back of my head I still (of course) know that my legs work and I get upset with the fact that my body isn't how I would like it to be.»

«Pretending is like a momentary relief, but that relief is never complete, it is like being hungry and eating, but never feeling satiated. So, in a way, it ends up being a kind of suffering, an eternal search for something that never comes.»

«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.»

Within the sample simulating disability (42 participants, as shown in Table 8), 12 stated that they simulate it every day, 8 several times during the week, 12 occasionally (from a few sessions per month to more extended periods between simulations), while 4 stated that they still practice the simulation but to a lesser extent than in the past and, lastly, 6 participants did not provide any indication of the frequency of these practices (Table 10).

Since some individuals have stopped practicing it, while others – with the words of one of our participants – “do it as much as humanly possible”, it might be interesting to set up a study entirely dedicated to the evaluation of neural correlates in the two groups. Recently, a study conducted by Saetta and colleagues (2020) showed a strong correlation between brain alterations and disability simulation. We will return to this study later on.

From an identity point of view, disability-related devices become an integral part of the being-in-the-world of these subjects (Heidegger, 1927). Everaerd (1983, 289) presented a particular case, in which the desire for amputation was closely linked to the use, to the *incorporation* we might say, of a wooden leg. Moreover, the latter represented for the subject the real pillar of desire; without it, as he declared, amputation would have been in vain. As already mentioned, this could be considered a very uncommon case. Indeed, it is necessary to specify that most of the subjects interviewed in our questionnaire only described the functional value of these objects – in terms of useful tools or as synonymous of the achievement of disability, something that would complete their disabled identity. In Xenomelia (the specific desire for leg amputation) the intention is not to destroy the functionality of the body. Typically, the functional component subtracted by the absence or inhibition of the target body part is compensated through the use of prostheses that allow behavioral continuity. Marie, a twenty-year-old with BID and GID, has described this phenomenon as “transabled paradox”. Malafouris (2013: 154) defines the blind man's stick – and technology in general – as an “enactive cognitive prosthesis”. One might wonder whether the artificial objects used during the simulation – or after amputation – by subjects with BID can be defined, to a certain degree and on an affective level, as existential prostheses.

However, what emerges is that, in some cases, material and visual culture can also play a role:

«I always felt different - but I saw Robocop at about age 13 and was fascinated by losing limbs and having them replaced with prosthetics. I realized that my feet were not really part of me and as such I'd rather have plastic feet that weren't so “disgusting”» (*a participant's response to our questionnaire*).

7. Thinking (and talking) about desire

From a phenomenological point of view, the intriguing aspect is that in BID the *judgement of ownership* remains intact. However, there is a lack of *feeling of ownership*, the implicit experience that permeates one's own body and the coincidence with it as a harmonious premise of the existence (Romano, Sedda, Brugger, and Bottini, 2015: 141).

«In the many cases of phantom limb, it is the body that perceives to possess or even seeks a disappeared part. The mind feels the weight of a “loss” and it is possible to imagine or experimentally demonstrate all the paths it has taken to reconstruct not only a representation, but also an embodied simulation by refocusing the mental states of the past. Less well known and studied are the cases in which it is precisely this loss that the body consciousness invokes. It is a question of anticipating an event that will happen, that must necessarily happen, and therefore imagine a future state of mind. However, this does not make this state of mind, expected for the future, less embodied than the ones induced by the cases of a loss of what has already been possessed in the past. Actually, this urge to lose a limb is stronger than the desire of those who want to regain a missing part of the body» (Freedberg and Pennisi, 2020: 12).

The BID presents a singularity, which has emerged since the study conducted by First (2005). So far, academic attention has focused mainly on sensations that reflect the incompleteness of the body, as happens in the phantom limb. In BID, on the other hand, individuals are tormented by a feeling of *hypercompleteness*.

In First's questionnaire, as much as 77% of the BID subjects of the sample indicates “feel whole, complete, set right again” (First, 2005: 923) as the main cause of their choice to amputate. Furth and Smith (2000) also suggest that the subjects interviewed by them consider the idea of amputating a way to feel more skilled and more fully functioning, more whole, more complete.

The logical argument is very clear: I feel *excessively* complete with that leg and, therefore, the amputation serves to bring my body back to completeness, becoming regular again as it should be. The function of that limb (or other organ) remains in the state of cognitive normality and, therefore, is re-implanted in the amputated part activating it through a mechanical substitute. The transition of functional ability therefore constitutes a transition from bodily technology to extracorporeal technology:

“I feel like an amputee with natural prostheses – they're my legs but I want to get rid of them – they *don't fit my body image*” (First, 2005: 922).

“I want to be deaf but I'd also use hearing aids to restore my hearing” (Marie, Makemed deaf: 21/4/2007).

It is not the functional component, therefore, that defines the conflicted relationship between mind and body. This component works both before and after the amputation and must still be satisfied. The xenomelic wants to hit the body, or rather: his *brain-body* wants to hit his *not-brain-body*, to use the terminology of Alva Noë (2009; in Hutto and Myin, 2017: *neural body and non-neural body*). The natural organs of this body are apparently fully functional. However, they are not perceived as harmonic parts of one's body: they are alien, depersonalized clippings, extraneous to both the scheme and the body image.

The problems that absorb the full-blown xenomelic are all technical: “will I be able to convince a doctor to amputate? how much will it cost me? And if I can't convince any surgeon how can I amputate myself without dying?”.

Moreover, BID forces the subject to immerse himself in a condition of social bodily solipsism. Some of the authors previously mentioned, have hypothesized that not only concrete simulations can decree neuroplastic effects, but also the imaginative activity of these subjects could contribute. Modern cognitive science does not consider mental images

as “pictures in the mind”, but emphasizes their embodied nature, primarily grounded in a partial reactivation of the sensorimotor system (Iachini, 2011; Meugnot et al., 2014).

The imaginative faculty animates a still-open debate. McGinn (2009) made a clear distinction between cognitive and sensory imagination. The first concerns a propositional attitude (that involves beliefs and concepts), while the second is based on the sensory dimension. In response to this dichotomy, other authors proposed a *multimodal spectrum of imagination* (Thomas, 2014).

Going into these topics goes beyond the scope of our work; however, we believe that also top-down processes can, at least, contribute to intensifying the desire for disability. As pointed out by some authors: «The more often a person thinks about being disabled, the more real the desire to fulfil this wish becomes” (Aner et al., 2018: 35).

As already mentioned, psychological therapies do not appear to be resolutive. Kröger and colleagues (2018) presented a questionnaire to 25 participants to investigate the effects of various therapeutic approaches, showing that 64% of these subjects never turned to psychotherapists or took psychopharmaceutical drugs. In our study, the percentage of those who have never turned to specialists is 56.1% (Table 11). Although it was not possible to determine the various therapeutic approaches followed by the participants, 50% of those who did psychotherapy (Table 12) stated that it did not help them, 25% stated that it did not help them with BID per se and 10.7% stated that the psychological path helped them to accept the disorder, mitigating their feeling of being bizarre. Instead, 4 participants did not provide any indication of the effects of psychotherapy (14.3%).

In other studies, some patients with BID reported that adopting psychotherapeutic methods helped them relieve anxiety and depression (Blom et al., 2012: 3), while others claimed that these sessions resulted in increased desire; according to Noll and Kasten (2014: 230), this happens because talking about BID induces patients to focus their attention even more on the desire, which persists and strengthens.

Recently, Grochowski and colleagues (2018) showed that BID – like *Body Dysmorphic Disorder* (BDD) – is characterized by a more significant number of mental images than the control group. Besides, contrary to what happens to individuals with BDD, it seems that mental images in BID are less intrusive and permeated by a positive attitude, so «parallel to real, everyday life, intentionally evoked mental images may often run as a permanent mental movie in the brain, which shows life as a person with the desired disability» (Grochowski, Bücken, Kasten, Osen, and Heinrichs, 2018: 9).

However, a significant presence of intrusive thoughts – which seem to decrease after amputation – has also been found in BID (Oddo, Thiel, Skoruppa, Klinger, and Steis, 2009: 66). Not surprisingly, some studies have investigated the similarities between BID and *Obsessive-compulsive disorder* (OCD) (Braam, Visser, Cath, and Hoogendijk, 2006), assuming the possibility that BID can be considered a sub-type of OCD, in which the simulation of disability could be considered as a control compulsion in response to repetitive ruminations about desire (Link and Kasten, 2015).

We asked our participants to describe the intensity and impact of these thoughts in their lives. For some of them «the feelings go up and down like an angry sea», in relation to stress levels, the attention paid, the type of activity performed and other circumstances:

«For me I guess BIID is a constant thing but at the same time it's kind of in the background? It's just feeling weird/off always to some degree but it's so amorphous it's difficult to pin it down. If I think about it too much it can be overwhelming and then all I want to do is get rid of the limb so I won't have to deal with it anymore.»

«They come up regularly. Weekly, or more than weekly. If I am not stressed, but have a lot of work, they come up weekly. If I am stressed and a lot of work, they come up daily or hourly. The thoughts transfer me into an alternate reality.»

«I have noticed that the extent of disconnection to my legs depends quite strongly on factors that would be expected to alter my brain's functioning. For example, a lack of sleep and even extremely small amounts of alcohol are two of my biggest triggers. Additional triggers include intense fright, and possibly excessive caffeine intake and stress (though these are more minor factors compared to the first three). Although I believe this is likely to be at root a neurological problem, I have lived the vast majority of my life with the belief that my legs should not function as they physically are able to. It is very possible that this has conditioned my brain to change the way it perceives my legs to the point where it is now impossible to distinguish cause from correlation.»

Other participants responded that they are always “hyperaware” of their bodily dissonance:

«The intensity fluctuates, but it's always there. Everywhere I walk, I imagine I'd be in a wheelchair; when I'm in bed I feel miserable about the fact that I'll have to get up again and when I sit down I imagine I'm in my wheelchair. This affects my mood, it feels like it is always a fight to push those thoughts away. It distracts immensely from everything else, work, friends, creativity etc. I think this makes that I'm not always performing to the best of my capabilities, because I spend so much time and energy on this internal fight.»

«I am surprised when I catch myself not thinking about it. I think about it every hour of every day. Not constantly every day, but the thoughts are always there in the background at least. The only time I have had relief is when pretending to be a high level quadriplegic with assistance [...]. Allowing myself to have the BIID thoughts has flipped a switch and made the suicidal ideation disappear. Of course allowing myself to have these thoughts also takes up a great amount of my time. I think it has contributed to the loss of one job and made it extremely difficult to start another job. I specifically chose my current job because it allows me time every hour or so to think of anything that I want. It is also structured enough that if I find myself completely distracted from my work I can figure out where I was and get right back into it. I spend my free time mainly online with others who understand me, chatting and role playing, or consuming related media. My relations in person have been neglected because of this.»

The Internet has represented a powerful turning-point for minorities and, more specifically, for those suffering from this disorder (Bruno, 1997; Davis, 2012). As Berger and colleagues (2005) pointed out, without the advent of the web, it would have been difficult for people with BID to establish such a network of information and contacts.

In this regard, we asked our participants what online communities represent to them and we have summarized the answers in three categories (Table 13). We have included in the “Positive” category answers such as «*It is a lifesaver! I have met other people like me and it is comforting that I can finally communicate with people like me*», or answers from those who have spent a lot of time on these platforms. In the “Neutral” category, we inserted answers like «*Just communities*». Lastly, in the “Negative” category we inserted answers like «*I now keep a minimal online presence in the BIID community as my past experience with it has been more about wallowing in depression than attempting to help each other*». As we shared the questionnaire within social networks, we believe that “not users” were invited to fill in the questionnaire by other participants.

The desire for disability has been defined by Charland (2004: 340) as «the first psychiatric disease manufactured in cyberspace». We disagree with this assumption. Some of our participants are over 70 years of age and report experiencing this discomfort since childhood. However, the reflections proposed by Davis (2011) might be interesting in relation to what we mentioned in the previous paragraph, about the engagement with material and digital things. Far from considering users (*prosumers*) and their content as separate elements, Davis argues that it is necessary to recognize that shared content itself can shape the identity of individuals. In this view, participation in these communities would

contribute to the prosuming of “transabled identity” and, at the same time, to the construction of the category “transableism” as a cultural variable of identity (Davis, 2011: 8-9).

Navigating these communities, we learned that the term “transabled” is not welcomed by all users, especially after it has rebounded in the mass media attracting feelings of blame from public opinion.

Finally, we assume that intersubjectivity, the sharing of one's experiences and self-recognition within a horizon of personal and collective meaning, can contribute to the apprehension and the maintenance of desire:

«I've had these feeling for several years, but they became more intense once I learned about the term BIID. It's nice to finally have an explanation/definition for what I'm feeling, but it also makes me more aware of it» (*a participant's response to our questionnaire*).

Beyond the virtual spaces, we asked the participants if they talked about their desire in the context of concrete relationships (Table 14). From our data, it emerges that 60.6% spoke about their condition (in Table 15 it is possible to observe specifically with whom they did so).

8. Conclusion

Recently, Saetta and colleagues (2020) published the most comprehensive experimental study focused on BID. The principal evidence found by the researchers were: a lack of intrinsic functional connectivity in the right paracentral lobule (rPCL) and the right superior parietal lobule (rSPL), interpreted as an inadequate anchoring of limb representations; atrophy of the left premotor cortex (IPMv) and the right superior parietal lobule (rSPL) which would suggest a deficit in multimodal integration; both functional and structural alterations in the rSPL, that would reflect an impaired body image at the highest level of integration (Saetta, 2020: 3). Furthermore, the authors correlated increased atrophy in the rSPL with a greater inclination to disability simulation, which would be the attempt of these subjects to mitigate the perceived discrepancy between their actual body and the desired one.

This study is precious, especially because it is conducted by a team of neuroscientists who have always underlined the importance of the psychological and sociological aspects inherent in this condition. For this reason, we wonder if the correlation between rSPL atrophy and disability simulation could also be read from the perspective of neuroplasticity.

Recently, Kasten (2019) pointed out the limitations of some brain theories, as these would not explain all cases of BID. According to the author, if the discrepancy between the physical body and the mental body resulted from a congenital dysfunction or damage in early development, there should be a congruent number of desires for legs and arms; moreover, the latter should be more recurrent, since the cerebral representation of the arm is more exposed in the cortex than that of the leg, and therefore would be more vulnerable (Kasten, 2019: 33). In this respect, our study shows a decisive disproportion between requests for amputation (Table 6). While the desire to amputate the legs was indicated by 35 participants (one leg or bilateral legs), only 4 participants indicated the desire to amputate the arms (one arm or bilateral arms). Also, 5 participants reported a mixed desire for amputation of legs and arms (one leg and one arm, bilateral legs + one arm, quadruple amputation).

Also, as Kasten pointed out, sometimes the focus of desire can change over time or can be directed to other parts after amputation (Sorene et al., 2006; Berger et al., 2005). In this regard, 60.6% of our participants stated that desire has never changed, Instead, 21.2% reported that desire has changed and 9.1% that it can change (Table 16).

The category “Changed” includes the following changes: 1) from the right leg the desire also extended to the left and right arm; 2) from paralysis to bilateral amputation (with an intermittent desire directed to the arms and sensory deprivation); 3) an initial doubt between right and left leg; 4) from one arm the desire also extended to one leg; 5) from bilateral amputation to one leg; 6) from the left leg to the right leg; 7-8) from the right leg has also extended to the left; 9) from the right leg to the left leg; 10) from paraplegia to tetraplegia; 11) a desire that over time has translated into the desire to be visually more impaired than before; 12) from the left arm to the right leg; 13) the height of the cut; 14) not specified.

The category “It can change” includes: 1) a participant who declared that the desire sometimes concerns amputation and sometimes paraplegia; 2) a desire for bilateral amputation which sometimes becomes a desire to be as deficient as possible; 3) a desire for paralysis which could be replaced by a bilateral amputation in order to live in a wheelchair; 4) bilateral amputation which sometimes becomes a wish for quadruple amputation; 5) indecision about being blind in one eye or both; 6) in addition to the left leg, sometimes the participant desires amputation of the right leg and right arm.

Furthermore, Kasten (2019) mentioned some cognitive-based changes, in which the preference of the limb to be amputated is related to functional limitations resulting from its absence. A small number of our participants responded as follows:

«I have always found several types of amputations interesting, however, bilateral amputation below the knee has solidified over time. But when I was younger, I was interested in arm amputations, paraplegia, and blindness as well. However, I imagine that the functional restrictions imposed by these deficiencies would be too great and I would not be happy to be so. But in a way, there is a desire in me to be as deficient as possible, in the sense that if there was a functionally perfect prosthesis of the arm, I think I would like this amputation too. And like the amputation of the legs, in intimate moments I would not like to use either the prostheses of the legs or those of the arms.»

«It changed from the right leg to the left leg after I started having problems with the left foot»

The last participant, however, reported that he had achieved amputation in his left leg and never regretted it. In this regard, we asked our participants if they have ever damaged any of their own body parts (Table 17). Participants in the category “Yes” have achieved the desired disability or have come very close to it (12,1% of participants). None of them said they regretted their choice. The category “Minor damage” refers to those cases involving mutilation or minor damage to the toes, fingers, eyes, calves (7,6%). 15.2% said they tried without success and 6% did not answer the question. Finally, 59.1% did not damage any body parts.

There is also another aspect that needs to be emphasized. We explicitly asked the participants whether the acquisition of a disability other than the aspired one could mitigate the desire to amputate or inhibit the unwanted parts. Out of 66 participants, it was found that only 13.6% of them said that this eventuality could “satisfy” them (Table 18).

Finally, in the last part of our study – the only closed-answer question – we presented the following scenario:

«Imagine a method which could fully restore your body integrity (with no collateral effects). Would you use it or would you still prefer to proceed with your desire?»

- Yes, I would opt for a therapeutic method.
- No, I would prefer to pursue my desire»

Our survey shows that 74.2% of respondents would prefer to achieve the desired disability (Table 19). This data could be a preliminary approximation of the degree of

participation relative to a hypothetical rehabilitation horizon. In a BID-centered book that also contains the patients' point of view, an academic physician with this condition wrote:

«It is reasonable to ask an individual with BIID whether (s)he would like to be cured of the desire for an amputation. Some may choose this. Many, including myself, do not want to be cured. When something has been part of one's psyche for as many years as BIID has been of mine – since my childhood – asking me to be cured of it is tantamount to asking me to change who I am» (in Stirn, Thiel, Oddo, 2009: 97-98).

However, as can be seen, a minority of participants are open to alternatives to surgery. About online communities, one of our participants said:

«People talk about how sexy they think they are, or obsess over what assistive devices they want/like, or justify their demands for surgery by falsely comparing what we go through to what trans people go through. Very rarely does anyone want to talk about how to just...live and learn to heal from it? It's alienating, especially when some biid people are so aggressive about the surgery thing that they actually refuse to talk about anything *but* amputation.»

In this study, we have tried to outline how body image can be, to a certain degree, a plastic process. In addition to a possible neurological origin, we have tried to highlight the role of a first phase of vulnerability in childhood, the neuroplastic retroaction related to simulation, the potential influence of culture and sharing of experiences. The primary purpose of this research was to reunite the brain with the living body, narratives and environment:

«The brain is formed by mental life; from early childhood on, mental structures come to be imprinted in the brain's structure, and the individual increasingly shapes his own brain through his actions and interactions [...] It constitutes a *system of open loops* that have been formed in the course of earlier interactions, and that are functionally closed each time the organism is interacting with a certain object or situation that it has dealt with before» (Fuchs, 2011: 197-198).

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APPENDIX 1

- *Section one: Living with BID*

1. Scientific literature has described BID as a paraphilia, an identity disorder or a neurological disorder. Beyond the scientific label, what does it feel like to live this condition?
2. When did the lack of bodily integrity emerge?
3. How intensely do BID thoughts occupy your mind? How do these thoughts affect your life?

- *Section two: Self and Body image*

4. It appears that people who live with BIID know that the target body part belongs to their own body. Despite this, they feel it shouldn't be. Please, describe your body image.
5. How do you feel the target body part? How does this experience differ from the experience of feeling the rest of your body? (for example, in terms of tactile, visual, motor and emotional feelings).
6. In your opinion, what is the cause of such a lack of consonance with the target body part to? would you say it is caused by its functionality or its presence?

- *Section three: Pretending behavior*

7. What does pretending behavior mean for you? (for example, a relief, a palliative, an additional frustration).
8. If you usually practice it, since when and how much do you practice it?
9. What do prostheses, wheelchairs, leg braces, crutches or similar tools mean for you? What is your relationship with these objects?

- *Section four: Target of desire*

10. Has the target of your desire always remained the same? If not, how has it changed over time?
11. If you accidentally lost a body part other than the target one, would this event satisfy you or would you still try to pursue your desire?
12. Have you ever amputated or damaged a part of your body? If so, have you ever regretted it?

- *Section five: Talking about desire*

13. What do online communities mean for you?
14. Have you talked to friends and family about your desire? Describe your experience (for example, the reasons why you did it - or why you didn't -, the reactions of people close to you, how you feel about it).
15. Have you ever followed a psychological therapy? If so, has it helped you in any way?

- *Section six: A Hypothetical Crossroad*

16. Imagine a method which could fully restore your body integrity (with no collateral effects). Would you use it or would you still prefer to proceed with your desire?
 - Yes, I would opt for a therapeutic method.
 - No, I would prefer to pursue my desire.

APPENDIX 2:

Table 1

AGE		66 PARTICIPANTS
18-30	45,45%	30
31-50	31,82%	21
51-75	22,73%	15

Table 2

CONTINENT		66 PARTICIPANTS
Europe	45,45%	30
North America	40,91%	27
South America	7,58%	5
Oceania	3,03%	2
Asia	1,52%	1
Africa	1,52%	1

Table 3

GENDER		66 PARTICIPANTS
Male	65,2%	43
Female	21,2%	14
Other	13,6%	9

Table 4

DISABILITY DESIRE		66 PARTICIPANTS
Amputation	71,2%	47
Paralysis	15,2%	10
Sensory Deprivation	7,6%	5
Mixed	4,5%	3
N.B.S.	1,5%	1

The “mixed” category includes: 1) a participant who has stated that he wishes to become wheelchair dependent, regardless of the type of disability required for this purpose, 2) a participant who has stated that he sometimes feels the desire to be a DAK amputee and sometimes to be paraplegic, 3) a participant who has expressed the desire to remove a leg and genitals. The last participant has already reached eunuch condition.

Table 5

GENDER AND DESIRE CORRELATION PARTICIPANTS						66
	Amputation	Paralysis	Sensory Depriv.	Mixed	N.B.S.	
Male	56,1%	4,5%	1,5%	3%	-	43 participants
Female	7,6%	9,1%	3%	-	1,5%	14 participants
Other	7,6%	1,5%	3%	1,5%	-	9 participants

Table 6

DISABILITY FORM		66 PARTICIPANTS
One-legged	33,33%	22
One leg, one arm	4,55%	3
One leg + genitals	1,52%	1
Bilateral legs amputation	19,70%	13
Bilateral legs + one arm	1,52%	1
Quadruple amputation	1,52%	1
One-armed	3,03%	2
Bilateral arms amputation	3,03%	2
Paraplegic	10,61%	7
Tetraplegic	4,55%	3
Blindness	7,58%	5
Dak amp. / paraplegic	1,52%	1
Wheelchair goal	1,52%	1
N.B.S.	6,06%	4

Table 7

ONSET OF DESIRE		66 PARTICIPANTS
Childhood (< 11)	72,73%	48
Youth (12-19)	21,21%	14
Adulthood (20 >)	4,55%	3
N.B.S.	1,52%	1

Table 8

DISABILITY SIMULATION		66 PARTICIPANTS
Yes	63,64%	42
No	13,64%	9
Not anymore	15,15%	10
Not yet	4,55%	3
N.B.S.	3,03%	2

Table 9

WHAT IT REPRESENTS.		42 PARTICIPANTS
Relief	50,00%	21
Frustration	2,38%	1
Relief and frustration	30,95%	13
Relief and shame	4,76%	2
Relief (but strengthens BID)	2,38%	1
Fun	2,38%	1
N.B.S.	7,14%	3

Table 10

SIMULATION TIMES		42 PARTICIPANTS
Daily	28,6%	12
Weekly	19%	8
Occasionally	28,6%	12
Most in the past	9,5%	4
N.B.S.	14,3%	6
These categories have been described in the section "Enacting disability".		

Table 11

PSYCHOLOGICAL THERAPY		66 PARTICIPANTS
Yes	42,4%	28
No	56,1%	37
N.B.S.	1,5%	1

Table 12

IT HAS HELPED?		28 PARTICIPANTS
Yes (self-acceptance)	10,7%	3
No	50%	14
Not with BID per se	25%	7
N.B.S.	14,3%	4

Table 13

ATTITUDE TOWARD ONLINE COMMUNITIES		66 PARTICIPANTS
Positive	78,8%	52
Negative	4,5%	3
Neutral	12,1%	8
Not user	3%	2
N.B.S.	1,5%	1

Table 14

TALKING TO SOMEONE		66 PARTICIPANTS
Yes	60,6%	40
No	36,4%	24
N.B.S.	3%	2

Table 15

TALKING WITH... WHO?		40 PARTICIPANTS
Family only	5%	2
Partner only	12,5%	5
Friends only	22,5%	9
Family and partner	2,5%	1
Family and friends	12,5%	5
Partner and friends	17,5%	7
Everyone	15%	6
N.B.S.	12,5%	5

Table 16

CHANGE OF THE DESIRE		66 PARTICIPANTS
Changed	21,2%	14
It can change	9,1%	6
Not changed	60,6%	40
N.B.S.	9,1%	6
The description of the categories “Changed” and “It can change” can be observed in their entirety in the Conclusions of this work.		

Table 17

SELF-DAMAGE		66 PARTICIPANTS
Yes	12,1%	8
Attempt	15,2%	10
Minor damage	7,6%	5
No	59,1%	39
N.B.S.	6%	4

Table 18

LOSING ANOTHER BODY PART		66 PARTICIPANTS
Not satisfied	51,5%	34
Yes, satisfied	13,6%	9
Not sure	22,7%	15
N.B.S.	12,1%	8

Table 19

REHABILITATION OR DISABILITY?		66 PARTICIPANTS
Rehabilitative method	25,8%	17
Achieving disability	74,2%	49