

# Being Whole After Amputation

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Assessing various studies on Body Integrity Identity Disorder (BIID), Müller (2009) claims that while psychology and psychiatry may have provided accurate descriptions of this rare disorder so far, they fail to actually explain it. According to her, only neurology can convincingly explain it: it is most likely that this disorder involves a congenital malformation in the brain. This claim about the cause of BIID is crucial for her answer to the question whether elective amputation is ethically justified or not. Taking for granted the neurological explanation of this disorder, she argues that elective amputation is not justified; if the problem can be located in the brain, it is the brain that should be treated, instead of amputating a healthy limb. Referring to the so-called four principles of medical ethics, she also maintains that elective amputation can also not be justified by a patient's autonomous decision, since it is not clear how autonomous such a person actually is.

In this review we would like to comment on two issues in Müller's target article: 1) her emphasis on a neurological explanation and treatment, and 2) her principlist ethical approach. As an alternative we would like to provide an existential clarification of BIID, and a phenomenological-narrative ethical approach which leaves the possibility for interpreting a person's autonomy against the background of the person's embodied experience and his or her life world.

Although it might be true that psychology and psychiatry research on BIID leaves us with unresolved questions of classification, we doubt whether resorting to neurology will resolve this problem. At least four objections can be raised here: 1) The suggestion that a neurological disturbance should be seen as the *cause* of a distorted embodied self-experience entails a crucial fallacy: every experience correlates with a certain neuronal activity, but this does not mean that neuronal activity causes experiences. Correlation does not necessarily imply a causal relation. 2) The neurological "explanation" is in fact no more than a hypothesis (Ramachandran and McGeoch 2007). 3) The idea that it may be better to adapt one's neuronal body image to one's body than to adapt one's body to one's neuronal body image does not take into account that manipulation of the brain is very risky and that an exact manipulation is in fact not (yet) possible. Neuroscientists who have established that transsexualism also correlates with a deviation in the brain, consider sex reassignment surgery as an adequate therapy (Cf. Swaab 2007) and do not even mention the possibility of a "causal therapy" which would influence the brain. 4) It is

true that one's sense of body ownership (or disownership in the case of BIID) can be explained in terms of "body image." Yet, the suggestion that this only includes the current state of one's neuronal map, as Müller does, does not provide any clarification of how someone actually experiences his or her own body. One's neuronal map constantly changes and adapts to changes in one's body, and this is very clear, for instance, in neuronal adaptation to prostheses and limb transplants (Giroux et al. 2001). However, successful neuronal adaptation does not automatically result in an experience that the incorporated body part is one's own (Slatman and Widdershoven submitted).

BIID is indeed a body image disorder. However, we believe that "body image," as the underlying makeup of one's embodied self-experience, should be considered as a dynamical structure which gives expression to our bodily existence (Merleau-Ponty 1945). Therefore, we seek an existential description of this disorder instead of limiting ourselves to isolated psychological, psychiatric, or neurological explanations. A human's bodily existence can be described as a two-layered way of being: one both *has* and *is* one's body. Or, according to phenomenological vocabulary, one's body can appear both as an object and as a lived-through experience of oneself: e.g. I can experience my hand as an object with certain qualities and I can experience it as *mine* (Slatman forthcoming). Being and having one's body imply two experiences which never totally coincide, comparable to the difference between touching and being touched (Merleau-Ponty 1964). We argue that bodily integrity or wholeness does not simply refer to a biological, functional, or neurological intactness, but rather involves a positive identification with the body one has. Bodily integrity thus presupposes a balance between the two experiences one can have of one's own body (Slatman and Widdershoven submitted). In the case of BIID this balance is disturbed; it is indeed a disorder of one's *integrum*, one's wholeness.

Therapy should therefore aim at a restoration of this wholeness, which means that one should encourage the process in which a patient can (re-)identify with the body he or she has. Hitherto, the most successful therapy is elective amputation. One may argue against this controversial therapy, since it clearly seems to run counter to the principles of non-maleficence (amputation of a healthy limb bears risks and will result in disability) and justice (treatment, rehabilitation, and early retirement of a disabled person imply high costs for society). But what to think of the participant in Melody Gilbert's documentary on BIID, who says that

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it was only after having his left leg amputated that he had become “whole?”<sup>1</sup> One might be inclined to state that even in this case the principles of non-maleficence and justice would pertain. Furthermore, one might doubt whether the wish to have the leg amputated can be regarded as an expression of rational autonomy. We, by contrast, would like to argue that applying the principles in such a way would do injustice to the case. From the perspective of bodily integrity, the operation is not an instance of maleficence, but of beneficence. The wish was based on a realistic view of the situation and a set of values which were clearly stable and crucial for the person. In such conditions, to approve of the person’s decision is to respect his bodily integrity. Before the amputation, the man could not identify himself with his actual body: he could not *be* the body he *had*. The amputation has enabled a process of re-identification: he finally can *be* the body he *has*, which results in an experience of bodily wholeness.

Without contesting the significance of principles, we maintain that they only gain their ethical value by properly applying them in particular cases. This obviously requires a thorough consideration of the case in question, and as we see it, the most adequate way to do this is by means of a narrative approach. Müller (2009) argues that BIID patients’ decision for elective amputation is not based upon autonomy but rather upon an obsessive desire. It is obviously very easy to call a persistent wish an obsessive desire, suggesting that the person in question is not competent in making rational decisions. We believe, however, that one cannot deny *a priori* that BIID patients are autonomous. Unraveling what a patient really wants requires “joint narrative work” (Widdershoven and Berghmans 2001). By this, we mean that one should build the patient’s narrative together with the patient. One might be inclined to think that a story is only the subjective representation of an individual experience. But then one forgets that a story also shapes one’s experience (Frank 1995). A healthcare professional can add to a story while interpreting what the patient (and his or her family) tells against the background of the patient’s life world. Instead of interpreting physical signs and experiences against the background of medical facts and social norms one should also ask: what is important for this very person in his or her life?

A BIID patient has the relentless experience that one of his or her limbs does not fit, resulting in an identity and integrity disorder. One’s identity and integrity is not simply

a question of (intact) anatomy and physical abilities. Rather, it has to do with a person’s identity as it becomes shaped in his or her life story: one’s experience of bodily wholeness thus corresponds with one’s narrative identity (Dickenson and Widdershoven 2001). It is only on the basis of our stories that we know what and who we are. Someone suffering from BIID may have the feeling that his or her experiences are not integrated in a meaningful unity: his or her life story may be disintegrated and therefore meaningless. If it becomes clear, on the basis of joint narrative work, that elective amputation is the only way to endow meaning to a patient’s life and life story, we believe that the performance of this (controversial) intervention is ethically justified. ■

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