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Diagnosing embodiment should become part of our repertoire

A response to "It's not a part of me, but it is what it is": the struggle of becoming en-wheeled after spinal cord injury

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LETTER TO THE EDITOR



Diagnosing embodiment should become part of our repertoire A response to "It's not a part of me, but it is what it is": the struggle of becoming enwheeled after spinal cord injury

Dear Editor,

It is with great interest that we read the article of Monforte and colleagues [1], putting forward an intrinsic case study of a patient with spinal cord injury (SCI) and his struggle of becoming so called "en-wheeled". Especially interesting was the patient's perspective on cyborg identity in relation to other technologies. The authors mention that while "Patrick neglected the possibility of incorporating the wheelchair" [1, p.3], it did not keep him from accepting or even celebrating the plates and screws stabilizing his spinal column. They elaborate by stating that this acceptance "signals the intricate nature of cyborgification, and the utility of the continuum for sensing the conflicts, paradoxes and nuances that enwheelment, and more broadly cyborgification, entails" [1, p.5]. We found this description of a continuum very striking, as it reminded us of comparisons our study participants have made between incorporating a wheelchair versus a neural implant.

The work of our group centers around the development and application of electrical neural implants in patients with SCI with the ultimate purpose of motor recovery. We have been interviewing our patients on their perspectives on tool embodiment, including discussing the possibility of tool incorporation of different (hypothetical) tools such as a wheelchair or a neural implant. Interestingly, several of our patients answered their questions from a perspective focused on (regain of) functionality. While most patients whole-heartedly considered their wheelchair to be part of their body ("these wheels are my legs"), they emphasized the difficulty envisioning the same level of embodiment for a neural implant, which in their opinion still had to proof its functionality.

From a perspective of phenomenological embodiment [2], we explain these answers by using the concept of "tool transparancy". In order for a tool to be truly part of a user's bodily representation (body schema), the focus on the tool itself, the user-tool interface so-to-say, needs to become transparent. By losing this opacity, we open up room for a focus on the user-environment interface instead, and as such a tool can become truly incorporated [2,3]. According to our patients, functionality clearly appeared to be a facilitating factor for this transparency. A wheelchair which is truly functional (i.e., allowing for mobility), can become more easily transparent than a wheelchair with a faulty wheel getting stuck at uneven surfaces, and a such drawing constant attention to itself. A multitude of other factors can facilitate this transparency as well [2], many of which are mostly patient-dependent, but also timedependent, emphasizing the fluidity of the concept, which the authors mention as well: "Across time, a person can move across the continuum without following a predetermined order" [1, p.5].

Lastly, the authors very justly mention that theories on embodiment can help "clients to incorporate assistive technologies in ways that support flourishing" [1, p.5]. What we think would facilitate this step from theoretical frameworks to clinical application, is considering embodiment as much a part of the healing process as any other biological parameter requiring diagnostics. In a previous paper we have dubbed this the "patient transparency diagnosis" (PTD) [2], which aims to determine the patient's current and desired level of embodiment. Not with the aim to freeze a patient's experience of embodiment in time, but rather to allow for the twosided reflection that is required to stay as open-minded and fluid throughout the embodiment process, as the concept itself is. Diagnosing incorporation, embodiment, transparency or en-wheelment, should be as much a part of our repertoire as the diagnostic process of the underlying diseases already are.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

- Monforte J, Smith B, Pérez-Samaniego V. 'It's not a part of me, but it is what it is': the struggle of becoming en-wheeled after spinal cord injury. Disabil Rehabil. 2019. DOI:10.1080/09638288.2019.1702725
- Tbalvandany SS, Harhangi BS, Prins AW, et al. Embodiment in neuroengineering endeavors: phenomenological considerations and practical implications. Neuroethics. 2019;12(3):231-242.
- Heersmink R. Embodied tools, cognitive tools and brain-computer interfaces. Neuroethics. 2013;6(1):207-2019.

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