 DOI: 10.3217/978-3-99161-050-2-055

Should BCIs shape experiences of communication of people with LIS, and if so, how?

B. van Balen[123]*, J. van Grunsven[3], W. IJsselsteijn[2], N.F. Ramsey[1,4], M.J. Vansteensel[1]

[1]*UMC Utrecht Brain Center, Department of Neurology and Neurosurgery, Utrecht, The Netherlands;*

[2]*Human Technology Interaction, Eindhoven University of Technology, Eindhoven, The Netherlands;*

[3]*Ethics and Philosophy of Technology, Delft University of Technology, The Netherlands;*

[4]*Donders Institute for Brain, Cognition and Behaviour, Radboud University, Nijmegen, The Netherlands*

*P.O. Box 85060, 3508 AB Utrecht. E-mail: b.j.vanbalen@umcutrecht.nl

Introduction: Locked-In Syndrome (LIS) is defined by (near) complete paralysis and intact cognition [1]. This condition profoundly shapes a person's experiences of communication [2]. Not much is known about the lived experiences of communication of people with LIS [3], which is related to the nature of LIS, where one loses almost all abilities to communicate and is reliant on augmentative and assistive communication (AAC) devices such as letter boards and eye-trackers to communicate. A promise of implantable communication-BCIs (cBCIs) is to 'restore' the communication abilities of people with LIS [4]. Considering the call for user-centered approaches to cBCI design [5], this raises the ethical question: should cBCIs shape the experience of communication of people with LIS, and if so, how?

Material, Methods and Results: We interviewed 8 people with LIS (4 female), 8 caregivers (5 female), and 10 medical professionals (8 female). The interviews with people with LIS were conducted with typing text, the others face to face. The goal of the interview was to explore typical experiences of communication, personhood, and wellbeing of people with LIS and familiar interlocutors. All interviews followed a phenomenological approach, where the goal of the interview was an in-depth, open exploration of the lived experience of the interviewee [6]. Interviews were transcribed ad verbatim and coded thematically following a grounded theory approach, making sense of the data in an iterative back and forth between the transcripts and the emerging themes. The following intertwined themes emerged to describe typical experiences of embodied communication: 1) intimate technological mediation of embodied interaction with the world (AACs shaping experiences of the voice, emotional expression, reliability, tempo and access to the world), 2) altering of familiar embodied expressions of aliveness (dehumanization, cyborgization, new communicational affordances in relation to skilled interlocutors, embodied diversity) 3) temporal delay in communication leading to a breakdown of flow (alienation from social life, failure of conversational flow).

Conclusion: For research and design of cBCIs, these results mean that user adoption stands to benefit from a focus on (tone of) voice, emotional expression, speed and reliability of communication, aesthetics of the device, designs that can adapt to the social setting and physical environment that a user is situated in, and subtle forms of embodied communication required for flow (nods, hmhm's, etc.). Moreover, these results imply a much-required shift from seeing a cBCI 'user' not as an individual but as a network that includes their close interlocutors.

Acknowledgments and Disclosures: We want to thank all the interviewees that participated in our study for sharing their experiences with us. Support by the Ethics of Socially Disruptive Technologies research program, funded by the Netherlands Organization for Scientific Research [#024.004.031]. We have no conflicts of interest to disclose.

References:

[1] American Congress of Rehabilitation Medicine. (1995). Recommendations for use of uniform nomenclature pertinent to patients with severe alterations in consciousness. *Archives of Physical Medicine and Rehabilitation*, *76*(2), 205–209.

[2] Van Balen, B. (2025). Can communication Brain-Computer-Interfaces read minds? *Phenomenology and the Cognitive Sciences,*

[3] Vidal, F. (2020). Phenomenology of the Locked-In Syndrome: an Overview and Some Suggestions. *Neuroethics*, *13*(2), 119–143.

[4] Metzger, S. L., Liu, J. R., Moses, D. A., Dougherty, M. E., Seaton, M. P., Littlejohn, K. T., Chartier, J., Anumanchipalli, G. K., Tu-Chan, A., Ganguly, K., & Chang, E. F. (2022). Generalizable spelling using a speech neuroprosthesis in an individual with severe limb and vocal paralysis. *Nature Communications*, *13*(1), 6510.

[5] Kübler, A., Holz, E.M., Riccio, A., Zickler, C., Kaufmann, T., Kleih, S.C., Staiger-Sälzer, P., Desideri, L., Hoogerwerf, E.J. & Mattia, D. (2014). The User-Centered Design as Novel Perspective for Evaluating the Usability of BCI-Controlled Applications. *PloS One* 9(12).

[6] De Haan S, Rietveld E, Stokhof M, Denys D (2015) Effects of Deep Brain Stimulation on the Lived Experience of Obsessive-Compulsive Disorder Patients: In-Depth Interviews with 18 Patients. PLOS ONE 10(8): e0135524.

Published by Verlag der Technischen Universität Graz