IS A BRAIN MACHINE INTERFACE USEFUL FOR PEOPLE WITH DISABILITIES? CASES OF SPINAL MUSCULAR ATROPHY

Yohko Orito, Tomonori Yamamoto, Hidenobu Sai, Kiyoshi Murata, Yasunori Fukuta, Taichi Isobe, Masashi Hori

Ehime University (Japan), Ehime University (Japan), Ehime University (Japan), Meiji University (Japan), Meiji University (Japan), Health Sciences University of Hokkaido (Japan), Waseda University (Japan)

orito.yohko.mm@ehime-u.ac.jp; yamamoto.tomonori.mh@ehime-u.ac.jp; sai.hidenobu.mk@ehime-u.ac.jp; kmurata@meiji.ac.jp; yasufkt@meiji.ac.jp; tisobe@hoku-iryo-u.ac.jp; horimasa@waseda.jp

EXTENDED ABSTRACT

Brain machine interface (BMI) or brain computer interface (BCI) systems have been recently developed and find application in diverse ways such as for rehabilitation, gaming, and marketing. In the field of social welfare, BMI systems are expected to be used as an assistive cyborg technology for people with disabilities who cannot move their limbs, as it enables communication between the brain and external devices via brain signalling (Orito et al., 2020). With these developments and wide availability of BMI, the possibilities and utilities of BMI systems, and the potential social risks of it are being observed (e.g., Bernal et al., 2023; Wahlstrom, 2018; Grübler and Hildt, 2014). The potential harm and ethical issues for people with disabilities should be analysed before BMI devices are commonly utilised in society. However, until now, access to such devices is limited for people with disabilities, and even if they are aware of BMI devices, they often require specialised engineers to operate them. Therefore, the potential benefits and risks associated with BMI devices among people with disabilities have not been sufficiently discussed.

Accordingly, the authors conducted experiments using BMI systems and semi-structured interview surveys with people with disabilities before, during, and after the experiment to investigate the ethical and social issues related to the use of BMI (Orito et al., 2022). In this experimental survey, participants were asked to wear a headset-type non-invasive BMI device (EEG input device) to operate a robotic arm remotely, and related semi-structured interview surveys were conducted. The question items were developed to investigate their attitudes towards the utilities and potential risks of BMI, considering the findings of previous studies (Orito et al., 2022 ; Orito et al., 2021a; Orito et al., 2021b; Orito et al., 2020; Murata et al., 2018; Murata et al., 2017; Isobe, 2013). Based on previous survey results, several ethical and social issues regarding the use of BMI devices in people with disabilities have been identified. However, in a 2021 survey, two participants with acquired disabilities commented that people with congenital disabilities should be targeted as participants for this type of experimental survey (Orito et al., 2022).

Therefore, two individuals with congenital disabilities were invited to participate in this study, and experiments and interview surveys were conducted in February and March 2023 at Ehime University in Matsuyama, Ehime Prefecture, Japan. All procedures were performed in accordance with the ethical standards of the Research Ethics Committee of the Faculty of

Collaborative Regional Innovation at Ehime University. Participant attributes are listed in Table 1. The two participants had spinal muscular atrophy (SMA) which is a condition involving muscle weakness and atrophy, although the symptoms differ between individuals and can vary greatly. The two participants used a wheelchair for mobility and required 24-hour care; however, they had different symptoms. Before the survey, the participants' health conditions were confirmed, interviews with Participant 1 were conducted online once after the experiment and other interviews were conducted face-to-face.

The survey results show that the BMI devices are expected to be useful for calling caregivers when they have emergencies, controlling digital devices such as personal computers and smart phones, and supporting communication with others in daily life. Participant 1 also stated that the BMI system is better used to support caregivers who have some degree of physical burden and that it should be used to improve the motivation and working conditions of caregivers. Participant 2 noted the value of computer-mediated support for people with physical disabilities; because only computer devices would be used to assist people with disabilities, there was no risk of human caregivers' unintentional privacy-related information leakage, assuming that their personal data were properly protected. While Participant 2 herself was not worried about such risks and is trusting of her caregivers, she expected that this cyborg-supported scenario would bring substantial benefits to people with disabilities who prefer to live as independently as possible and are less willing to develop close relationships with caregivers.

Table 1. Experimental participants (n = 2).

ID	**Age**	**Gender**	**Types of disabilities, conditions**	**Expectation/anxiety about the experiment (Weak 0–Strong 7)**
1	40s	Male	Spinal Muscular Atrophy. He can move only the thumb of the right hand. Usually, he operates a PC with his jaw and breath, and a smartphone with his thumb. He also has a tracheostomy, and cannot speak when equipped with a ventilator during rest or sleep.	6/2
2	30s	Female	Spinal Muscular Atrophy. Her body is inclined, and she does not use a respirator but has a respiratory illness; one of her lungs is partially collapsed. She can move her hands and neck freely.	5/2

Both participants also expressed concerns about the operational risks and issues regarding the use of BMI and implantable BMI. For example, they would be forced to assume the risks caused by malfunctions or errors in the device itself, and maintaining electronic power to operate the devices would always have to be considered. The potential for these incidents makes them anxious and evokes the need for a multi-layered backup system. Participant 1 was also worried

about the implantable BMI, such as negative effects or serious damage caused by the surgery on his body, especially as his muscle abilities are already compromised.

In addition to these practical issues, the two participants did not prefer to use BMI devices or cyborg machines to maintain their lives or be cared for; rather, they would like to be supported by a human caregiver. Participant 1 commented that when he used or was cared for by an emotionless machine, his human emotions seemed to disappear, and he also became an 'emotionless machine'. Participant 2 also stated that while it may be easy to control her body and communicate her intentions through BMI devices and brain signals, she was uncomfortable with her intentions being regarded as 'code' in the manner of an object. She said that it would be sad if she were supported like a physical object.

In terms of privacy, Participant 1 had no serious concerns regarding BMI usage, and he expected that his information collected through BMI devices would be used for future research and the development of assistive devices for people with disabilities. Participant 2, however, believed that while it is useful for brain signals to be used to control the BMI device, it is not permissible to make this information available to the public or third parties, and to use brain signals to analyse and predict their intentions without agreement.

In contrast, the overall responses to the semi-structured interview survey among the two participants suggested that people with disabilities tend to be left in environments where they are isolated from educational opportunities or general communication, making it difficult for them to self-determine and make autonomous decisions regarding the use of technology, including cyborg technology, in an appropriate manner. This implies that it is important to recognise the background and issues on autonomous decisions faced by people with disabilities when applying cyborg technology.

KEYWORDS: Brain-machine interface, support for people with disabilities, cyborgisation, spinal muscular atrophy (SMA).

REFERENCES

Bernal, S. L., Celdrán, A. H., & Pérez, G. M. (2023). Eight Reasons to Prioritize Brain-Computer Interface Cybersecurity. *Communications of the ACM*, 66(4), 68-78.

Grübler, G. and Hildt, E. eds. (2014). Brain-Computer Interfaces in their ethical, social and cultural context. Dordrecht: Springer.

Isobe, T. (2013). The perceptions of ELSI researchers to Brain-Machine Interface: Ethical & social issues and the relationship with society. *Journal of Information Studies*, 84, 47-63 (in Japanese).

Murata, K., Adams, A. A., Fukuta, Y., Orito, Y., Arias-Oliva, M. & Pelegrín-Borondo, J. (2017). From a science fiction to reality: Cyborg ethics in Japan. *Computers and Society*, 47(3), 72-85.

Murata, K., Fukuta, Y., Orito, Y., Adams, A. A., Arias-Oliva, M. & Pelegrín-Borondo, J. (2018). Cyborg athletes or technodoping: How far can people become cyborgs to play sports? Presented at ETHICOMP 2018, 25 September 2018, Retrieved from https://www.researchgate.net/publication/327904976_Cyborg_Athletes_or_Technodoping_How_Far_Can_People_Become_Cyborgs_to_Play_Sports.

Orito, Y., Yamamoto, T., Sai, H., Murata, K., Fukuta, Y., Isobe, T. & Hori, M. (2022). The social implications of brain machine interfaces for people with disabilities: Experimental and semistructured interview surveys, *Proceedings of the ETHICOMP 2022: Effectiveness of ICT ethics – How do we help solve ethical problems in the field of ICT?,* 487-501

Orito, Y., Yamamoto, T., Sai, H., Murata, K., Fukuta, Y., Isobe, T. & Hori, M. (2021a). How a brain-machine interface can be helpful for people with disabilities?: Views from social welfare professionals In Mario Arias Oliva, Jorge Pelegrín Borondo, Kiyoshi Murata and Ana María Lara Palma (eds.), Moving Technology Ethics at the Forefront of Society, Organisations and Governments, 103-115.

Orito, Y., Yamamoto, T., Sai, H., Murata, K., Fukuta, Y., Isobe, T. & Hori, M. (2021b). The ethical issues of the use of BMI in social welfare: An experimental and semi-structured interview study with professionals, *National Conference of Japanese Society for Management Information 2021 Spring* (in Japanese).

Orito, Y., Yamamoto, T., Sai, H., Murata, K., Fukuta, Y., Isobe, T. & Hori, M. (2020). The ethical aspects of a "psychokinesis machine": An experimental survey on the use of a brain-machine interface. In Arias-Oliva, M. et al. (Eds.). *Societal Challenges in the Smart Society* (pp. 81-91). Logroño, Spain: Universidad de La Rioja.

Wahlstrom, K. (2018). Privacy and Brain-Computer Interfaces, Doctoral Thesis, De Monfort University, U.K.