In dialogue with the real experts: technical, ethical, legal and social requirements for BCIs as access technologies

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Abstract

This preliminary study describes the assessment of BCI technology by people with neuromuscular disorders (N=7) and high spinal cord injuries (N=9) from a technical, ethical, legal and societal perspective. It becomes clear that people with disabilities could and should greatly contribute to the design of assistive technology.

1   Introduction

The field of brain-computer interfacing (BCI) is rapidly expanding its application areas. Scientific and technological endeavors typically focus on feasibility, validity and reliability of such emerging technologies. However, the transfer of BCI technology to the clinic may be slow or difficult if practical issues as well as ethical, legal and social issues are not properly and timely addressed.

Previously, Nijboer and colleagues interviewed rehabilitation specialists (N=28) what type of users could be potential target users for BCIs as access technologies and what design requirements BCIs should fulfil to be usable and pleasant technologies for such users [1]. Recommended target users are only those who can hardly or not at all use alternative access technologies. People in the locked-in state (resulting from late-stage amyotrophic lateral sclerosis, multiple sclerosis, spinal muscular atrophy type II or classical or total locked-in syndrome) and people with high spinal cord injury (C1/C2) could be target users. Specialists caution engineers and developers that these users may have many concurring problems such as sensory or cognitive impairments and epileptic seizures. In addition, transferring BCIs from the lab to the daily life of such target users will need a grounded consideration for ethical, legal, social and cultural issues.

In this study we investigate the experience and opinions of people with neuromuscular and muscular diseases (N=7) and people with high spinal cord injuries (N=9) on such issues after they 1) have been educated about BCIs, 2) have had the opportunity to experience a BCI and 3) had the opportunity to discuss the technology with each other. These user groups are interesting to compare. One group, with disorders which have progressed sometimes from childhood, has a lifelong experience with assistive technologies. The people with SCI have had years of experience with access technologies for able-bodied people (keyboard and mouse) and now find themselves having to use access technologies for disabled people. In addition, people with SCI do not have to anticipate further functional decline, whereas people with progressive disorders do.

2 Methods

Seven participants with progressive neuromuscular or muscular diseases (NM group) and nine participants with high spinal cord injuries (SCI group) were recruited through the Dutch Neuromuscular Diseases Association and the Association Spinal Cord Injury (see Table 1). Participants were invited to attend workshops (one workshop for each group of users) entitled 'The possibilities and impossibilities of Brain-Computer Interfaces'. The two workshops were prepared together with the directors of the associations and one of the participants to ensure that the program was relevant and satisfactory for participants. Workshops were free of charge and held in accessible buildings in a central location of the Netherlands to ensure equal access. Participants were reimbursed for travel costs and provided informed consent before the workshop for their opinions to be recorded on audio and video and pictures to be made.

Participant	Diagnosis	Age	Verbal Communication	Wheel chair	Artificial ventilation	Access technology in use
NM group						
1	SMA type II		Slurred	Yes	Yes	Sip & puff device
2	ALS	52	Speech synthesizer	No	No	Keyboard/mouse
3	SMA type II	38	Normal	Yes	Yes	Finger switch
4	SMA type II	33	Slurred	Yes	Yes	Eye tracking
5	Distal SMA	60	Normal	Yes	No	Keyboard/mouse
6	SMA type II	23	Normal	Yes	No	Keyboard/mouse
7	SMA type II	21	Normal	Yes	Nighttime	Keyboard/mouse
SCI group						
1	T5	61	Normal	Yes	No	Keyboard/mouse
2	C4/C5	45	Normal	Yes	No	Keyboard/mouse, mouth switch
3	C3/C4	39	Normal	Yes	No	Head switch
4	C3/C4	51	Normal	Yes	Nighttime	Chin joystick
5	C4/C5	61	Normal	Yes	No	Keyboard/mouse
6	C3/C5	38	Hushed	Yes	No	Keyboard/mouse
7	C5/C6	30	Normal	Yes	No	Adapted keyboard
8	C5/C6	52	Normal	Yes	No	Keyboard/mouse
9	C6/C7	60	Normal	Yes	No	Keyboard/mouse

Table 1: Overview of participants. NM = neuromuscular; SCI = Spinal Cord Injury; SMA = Spinal Muscular Atrophy; ALS = Amyotrophic Lateral Sclerosis. Hushed = cannot produce normal voice loudness.

The workshop followed a 3-step format which we dubbed the "give-and-take" approach. First, participants were educated about the technical components of BCIs, available neuroimaging techniques and types of applications. They were also presented with some of the major challenges the field of BCI faces (e.g. universal design, reliability issues, limitations to information transfer rate, sensors). Second, two participants in each workshop were offered to try out a BCI as an access technology to operate a commercially available computer access software (The Grid 2 from Sensory Software, see for a description [1] and for a video of a participant trying the demo: http://youtu.be/gf3C_lAHT8U). The rest of the group watched and asked questions. Third and finally,

we held a focus group interview with the participants to assess the technology they had seen in the demonstration and the BCI field at large. Participants were prompted with predefined questions, but also encouraged to bring up other topics they found (more) important. The interviews were transcribed verbatim. Here we offer a preliminary descriptive overview of take home messages given by participants.

3 Results

The focus group interviews provided recommendations from the participants on 4 different levels: technical, ethical, social and legal (policy) issues. In addition, a philosophical outlook on human identity was discussed.

In general, participants were positively surprised by the state of the art of the BCI field, the effectiveness and the feeling of the BCI prototype. On a technical level, participants in both groups agreed that they could not yet see the added functional value of current BCIs over existing communication aids, although some participants in the NM group could imagine that BCIs could have added value for them in about a year, because they anticipated a further decline in function such that operation of their current aid would no longer be possible. Both groups indicated that the usability of the system needs improvement. In both groups there was a strong interest for operation of a robot arm rather than a communication aid, which seemed to be motivated, firstly, by the availability of reliable communication aids in the NM group and the ability to speak in the SCI group and, secondly, by an interest to expand or enhance current functionality rather than just repair functionality.

This was often accompanied by a wish to have electrodes implanted in the brain for practical reasons: 1) sensors would be always in place (no need to bother caregivers), 2) the BCI would be less bulky and less prone to get damaged by outside factors, and 3) invisible sensors are more esthetically appealing.

Many participants seemed reluctant to discuss ethical issues and rather discussed practical issues, but when prompted with questions such as "what would you be afraid of?" participants recognized that ethical problems can be practical as well and indicated that agency was important. They want to feel sure that the BCI does not *"go out of control"* or *"takes over control"*. Also, the surgery for implanted sensors was perceived as risky, in particular for people in the NM group, since anesthesia is often very complicated if not impossible for these people. Nevertheless, a few participants said they *"would risk it"* if it gave them better functionality. Participants with neuromuscular disorders advise to do the surgery in an early stage of the disease and, if possible, in combination with the surgery for other life-sustaining measures, such as the tracheotomy.

Participants did not identify legal issues such as liability problems or see the need for special laws, but they did discuss reimbursement policies. For example, mainstream technologies, such an iPad, are not reimbursed even if these technologies would sometimes be the best solution for some people with disabilities. Instead, they have to make a choice out of special technologies for disability. Participants foresee difficulty in obtaining financial reimbursement for BCI technology. One participant said: *"It is also a money thing of course. As long as I can use a puff-and-sip device, we'll use that. It is cheaper than a BCI"*.

Societal issues related to BCI technology and assistive technology were discussed at length. Many participants indicated that they did not want to wear a cap with sensors on their head unless it was disguised as conventional headwear. The technology that surrounds people with disability, such as communication aids and wheelchairs often scare people in society to such an extent that they literally turn their back when a person with a disability comes in sight. Hence, any BCI technology that would attract even more attention to persons with disabilities could potentially exclude them further rather

than include them in society as intended. Participants stress the fact that esthetical BCI design is therefore of utmost importance. On a more philosophical level we shortly discussed if BCIs could change the boundaries between humans and technology, but participants mostly agree that such boundaries have long changed for them since they are so dependent on technology anyway. They are not afraid of the cyborg idea. Rather they would rather embrace it.

4 Discussion

Compatible with previous studies [2-4], the preliminary study presented here showed that participants have stringent technical requirements concerning the usability of the overall BCI system (efficiency, robustness, esthetics of the cap, multiple users). After reviewing the current state of the art of BCI technology, participants did not yet see an added value of BCIs for themselves. However, they strongly endorse further development and would like to be involved in the process.

User involvement in technology design should not necessarily be restricted to the definition of technological requirements. This study shows that participants also have ethical requirements about agency and (timing of) risks. Agency is essential for feeling safe, for self-determination and for dignified living, especially for users with severe disabilities whose lives literally depend on technology. This study also shows that users with disabilities are interested in implanted electrodes. However, people with progressive neuromuscular disorders recommend that surgery should happen at an early stage in disease onset when the risk of anesthesia is lower. This view contrast the view of most scientists and ethical committees that surgery for a BCI should be a 'last option'. A recommendation could be to investigate scenarios in which surgeries happen at an early stage. Compatible with [5], most participants felt no need for special BCI regulations. Legal and policy recommendations focus on reimbursement issues (cost-effectiveness and robustness related to maintenance costs). Finally, end-users know – as no other - how society reacts to disability and assistive technology. When the appearance of BCIs does not improve, BCI technology risks to exclude people from society rather than to include them.

In conclusion, it becomes clear that people with disabilities could greatly contribute to the design of assistive technology and provide expertise into the ethical, policy and societal issues that must be addressed for successful technology transfer to the market. Thus, it is strongly recommended that potential users are involved – as experts – in the earliest stages of research and development of BCIs.

References

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