The Ethical and Practical Issues Surrounding the Design of Assistive Technology for Individuals with Severe Physical Disability and Complex Communication Needs.

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ABSTRACT

Assistive technology (AT) has the potential to improve the functional abilities of individuals with severe physical disabilities. Brain-computer interfaces (BCI) have gained interest for this purpose due to their ability to be used by individuals with no motor abilities. This paper describes the ethical and practical issues our research team encountered while researching the usability of a BCI-AT for people with severe cerebral palsy, who were non-verbal. We encountered issues around gaining sustained participation in our project, participant burden, dissonance between consent of caregivers/guardians and assent from our participants and obtaining feedback from proxies. Furthermore, before testing the BCI-AT prototype, our research team engaged our participant group through an immersion approach. This paper discusses this process and the ethical concern of potential coercion by taking this approach. Discussions around different approaches that researchers in this area take will make it possible to overcome issues which are commonly encountered, and enable more reliable and valid participatory research opportunities.

Author Keywords

Brain-computer interface, cerebral palsy, consent, researcher burden, assistive technology, complex communication needs, authenticity and trust.

ACM Classification Keywords

H5.2 User Interfaces: Prototyping, Evaluation/methodology, user-centered design.

INTRODUCTION

Assistive technology (AT) is an umbrella term that is used to describe any equipment or systems designed specifically to increase and maintain a person's functional abilities, such as touch screen tablets or speech synthesizing systems (Campbell, Milbourne, Dugan & Wilcox, 2006). Designing usable AT for individuals with severe cerebral palsy (CP) and complex communication needs (CCN) can be challenging. For example, designers need to ensure that systems are not only accessible, but also intuitive. Developers need to look beyond the individual and understand how people in their support network (caregivers, teachers, families, friends) interact with the human-technology system designed to support the individual (Kintsch & DePaula, 2002). Being empathetic to the needs of people with CP and those who support them can enable researchers, designers and developers to create solutions tailored to stakeholder specific needs and preferences, thus decreasing the persisting issue of technology abandonment (Kintsch & DePaula, 2002). However, this process can elicit a plethora of ethical issues.

All ethical principles require that research concerning human participants to be conducted in a way that respects the rights of the individuals concerned. More specifically, the United Nations (UN) Convention established what human rights principles signify in respect to individuals with disabilities (United Nations, 2006). Central to these are respect for their inherent dignity, individual autonomy (including freedom to make one's own choices) and independence. Research that involves people with disabilities would benefit from appropriate engagement with them (and their support networks), as it may enable researchers to frame their questions better, test the

validity of the conceived methods, and aid in the understanding of research findings (National Disability Authority, 2009). Furthermore, it is essential to address the unique and individual needs of participants, ensure ongoing assent/consent, and foster trusting relationships with all involved in that individual's life.

In 2013 we began research into brain-computer interface (BCI) technology as a form of AT for individuals with CP. A BCI is a new emerging form of human-computer interface technology that enables control of a computer through modulation of neuro-physiological processes (Neuper, Muller, Kubler, Birbaumer, & Pfurtscheller, 2003). With training, individuals can learn to control specific neural activities that can be used as commands in computer applications to enable, for example, communication. Typical AT systems require physical interaction, but often, our clients have unpredictable, if any, physical movements. Due to compromised motor control of the individuals with severe CP with whom we are working, BCIs may be a viable option, as these systems only require users to control brain activity.

This paper will firstly discuss the approaches taken to introduce this novel technology to a traditionally cautious and guarded community. Secondly, it will outline the ethical issues that emerged during our research into designing a prototype for a BCI training paradigm for individuals with serve CP and CCN.

DISRUPTIVE TECHNOLOGY

Familiarising Our Participants with Brain-Computer Interface Technology

BCIs are a novel form of technology; therefore, no one in our participant group had ever heard of, nor interacted with this technology before. Before consenting to participation in our research it was important for them to gain a comprehensive understanding of the technology, interact with the researchers (those with whom they would interact throughout the duration of the experimental protocol) and understand both the objectives of the research and the expectations of participations, such as the nature of the tasks, time commitments and use of the research results.

To engage the participants and their individuals in their support network, we ran four presentation and demonstration sessions for our potential participants, their caregivers and people within their support network (teach aides, special education teachers, occupational therapists, physiotherapists and speech and language therapists). It took us a few months to gain interest from the organisations we contacted. They commented that they were busy, unsure about the relevance of our research and feared the logistics of fitting us in. However, once we had one successful interaction, this opened up doors to others.

The presentations familiarised our potential participants with our research team and the technology, enabled them to ask questions and discuss any concerns (some used communication systems that required a prolonged time to type out their questions, therefore they also had the option of emailing us with their concerns), as well as offer the opportunity to test the technology. As a result, they were able to make an informed decision about whether they would be comfortable working one-on-one with members of our research team and whether they were genuinely interested in taking part in the study.

The presentations also elicited active involvement, in which we were able to collaborate and consult with people with disabilities. This helped us understand the aspects of the research that were most relevant to the people for which it was designed, and allow us to reflect on how beneficial it would be in terms of delivering meaningful outcomes, and whether it was going to be conducted in a way that was sensitive to the their needs. McClimens (2008) notes that such active involvement can increase the quality of research, promote informed consent and aid the recruitment of participants.

Meaningful Outcomes

Meaningful outcomes were of grave concern for caregivers and support staff at the special education schools attended by some of our participants. For example, during our first meeting at a special education school, staff reported feelings of being disappointed by previous researchers who had come to their school, done the bare minimum to complete a paper or a degree, and let down both the staff and their students by not improving the status quo as had been promised. It was important that we communicated the realistic goals and outcomes of our research., and emphasize that the students were participating in research, they were not trialing the BCI system to then adopt as AT for themselves. Some parents had high expectations about what the technology could enable their children to achieve, and it was crucial that we did not follow in the footsteps of our predecessors, and let down our participants. However, we did agree that if the trials were successful, then we would implement a set up for one of their classrooms. The justification for this was that it would further our knowledge on how the technology works outside of research settings, in the hands of real potential consumers.

ETHICAL ENCOUNTERS

Limits of Human Research Ethics approval

During our research we found that it was difficult to predict all of the ethical encounters prior to conducting the studies. This meant that the human research ethics applications that were submitted were in a sense "best case scenarios", and many adjustments to the study protocols were made based on our interactions with participants. A pilot study may help tease out some of these ethical encounters, however due to the diversity in our participants' conditions, we believe that adjustments to the research protocol would still be required.

Respect for differences as research participants

To respect the needs of our participants, we chose wheelchair accessible venues for group sessions, and attended the participant's preferred venue for one-on-one sessions. Our participant's had high needs, therefore even wheelchair accessible bathrooms were not impossible for them to use, as they required hoists.

Furthermore, transport to locations would have required additional time and financial burdens for them and their families. Ensuring that our participants and individuals within their support network were comfortable and not inconvenienced was of utmost importance to our research, especially due to the need for their on-going participation over a two-year period.

Burden to participants

All of our participants with CP had limited stamina and required regular breaks during all of our studies. Their wellbeing was of primary concern. The research design and protocols allowed for rest and breaks as required. For example, during our focus groups we arranged formal breaks every hour for the three-hour duration, and openly expressed that participants could leave at any point and without penalty.

We found that trialing the prototype BCI system created a burden on the participants. Our experiments were both physically and cognitively demanding. The commercially available BCI used for the experiments was found to be uncomfortable. Therefore, there were numerous rest intervals during each trial session. These continuous rest breaks affected the results of our study, as we were often left with only 10 minutes worth of meaningful interaction with the BCI per session- sometimes none because we spent the duration of the session trying to get the participant in a comfortable state. This is an ethical dilemma of all researchers who work with individuals with CCN. They must remember that the well being of the participant supersedes and need for research outcomes.

Due to the severity of their physical conditions, our participants also battled a number of illnesses, such as, epilepsy and pneumonia. This meant that we were unable to repeat our studies in the same manner with each participant, and for individual participants, there were variations within each session. An ethical issue that resulted was the fact that effectively we gained ethics approval for "best-case scenarios". Throughout our trials we had to make individualized, unpredictable changes, to suit the needs of each of our participants. This made it impractical to reapply for each of these individualized changes as the changes depended on individual participant responses and their comfort levels on the day of each experimental session.

Although respondent burden raised issues around reliability and validity of our results, in a sense these interactions revealed some practical issues inherent to the way BCI technology is currently designed and used. If a user cannot stay awake due to their anti-seizure medication, they won't be able to use a BCI. Similarly, if it takes 20 minutes to position the user in their wheelchair so that BCI can sit in the appropriate position, then this is also impractical.

During our interviews, the teachers at the special education school also commented, retrospectively, on the impact that our trials had on their timetable. The schools with which we worked were very supportive, but at times they were understaffed making it difficult for them to arrange a communication partner/caregiver to attend trial sessions. There were even a number of occasions where the school principal had to accompany our participants. At the time of the study, we were unaware of this burden, and in the future it is important to ensure that the teachers feel comfortable discussing these needs with the researchers. This information must also be discussed openly in the participant information sheet and consent from all possible teachers/aides/therapists is required before commencing the research. Not only are we taking up the time of our primary participants, but also the entire network of individuals who support them.

Use of proxies

Individuals who speak on behalf of others are referred to as "proxies". They can decide whether to consent to a person's participation in research, they may also help interpret research information and aid in answering questions and provide feedback to researchers. The National Disability Authority (2009) suggests that in order to respect the autonomy of individuals, the use of proxy informants should be minimized.

We accept that the data we obtained may have been tainted due to being processed through another person. However, for our participant group, it was critical to gain insight from these proxy sources, due to our inexperience with their forms of communication and individual needs. Our participants were non-verbal, some used coded communication techniques (for example eye movements to spell out letters of the alphabet), others could only communicate using "yes"/ "no" responses by moving an arm or looking at communication cards that were then interpreted by a proxy.

Obtaining continuous assent/consent

The BCI device that we employed in our research was not ergonomically designed to suit our participants' needs. Therefore, our participants felt very uncomfortable during most of our interactions. Halfway through our trials, two of our participants, who were under the age of 16, clearly showed that they were no longer interested in participating in the research. They indicated this by making vocal attempts, moving their heads backwards to make the headset fall off, and crying. Although we took these actions to mean definite discontinuation in the study, their caregivers and teachers disagreed and tried to push on with trials. These actions revealed clear ethical conflict, where the person who consented on behalf of the participant wanted them to continue, but we needed to gain assent from the participant in order to do that. The loss of these participants could potentially have had a negative impact on our research results. This experience was conflicting for us as researchers, as we could have continued with the study, by accepting the feedback and consent from the support network who expressed that the participants were fine and just having a bad day.

To address this ethical concern we explained to the individuals within their support network about the ethical implications and potential harm of continuing to conduct the research when we know that the participant no longer wishes to take part. This open communication did not negatively affect our relationships with participants and

their support network. Instead of seeing the events as a loss, we turned it into learning, by working together to establish design features (e.g. physical support, hardware and software features) that could mitigate problems for future research.

These situations enabled deeper reflections on how researchers might design to better capture continuous consent throughout the research process. In such settings, we need to be more aware and sensitive to how participants may be feeling, especially when they have complex communication needs. Although it may be clear in consent and assent forms that participants may withdraw from the research at any time, we need to also be weary of the fact that there are discrepancies between the wants of those consenting for them. It may be necessary to explicitly ask participants at the beginning of a trial if they are up to the task, and if they wish to continue participation. Sharing the experience of this research during future recruitment may also help participants make a more informed decision.

Authenticity and Researcher Integrity
As researchers working with people who have severe health problems and who had negative experiences with previous research projects, we felt that it was particularly important to aspire towards researcher integrity. Connolly (2003, as cited in the National Disability Authority, 2009) states that researcher integrity consists of honesty, objectivity, rigour, diligence, openness, social responsibility and relevance, fairness and reflection on practice.

To help us establish researcher integrity, we took the time to truly immerse ourselves in the disability community in Auckland before we began recruiting participants for the research project. Members of our team joined different societies, attended functions, joined online forums, held information sessions, and even became caregivers and disability advocates in order to understand, first hand, the daily experiences of our participants. These practices enabled us to be diligent in learning about the acceptable types of behaviour and language, what platitudes to avoid, build trust, and as develop genuine empathy- as we achieved a lived experience. There is only so much you can learn from interviewing and surveying people, and gaining advice from supervisors and/or mentors. Actually becoming a member of the community can enable more in-depth insights, especially when your participant group struggles to use traditional means of communication and their primary caregivers, who are likely to be their communication partners, are burdened with the responsibilities of looking after a person with severe disabilities and health complications. The double-edged sword here is whether applying these immersion techniques can be seen as coercion, as the researchers had interacted and established relationships with potential research participants outside of the research environment.

We felt that transparency/honesty about our positions may be the reasons why the immersion helped us overcome the perception of coercion. In the beginning of the research project we connected with organisations based on our need to understand the potential for BCIs.

We used this as the foundation for building relationships with end-users and their families. Therefore, the interconnections grew organically and were mostly initiated by members of the community. Through this method, caregivers and health professionals indicated that they felt appreciated as people and co-designers, rather than just 'subject' to extract data from inside, of a research lab.

Interactioning with the disability community helped us reiterate on our research approach to address research rigour, relevance and reflection on practice. For example, instead of simply testing the usability and feasibility of BCI technology, our immersion process taught us about the extensive problems people face when acquiring and learning to use assistive technology, from the funding application process through to issues with service delivery. If we did not go through the immersion process, then our research would have been one-dimensional, leading to insubstantial research and design outcomes.

Lastly, researcher behaviour not only affects those participating but also the chances of future researchers being able to work with the same or similar group of people. If we were not authentic and did not achieve research integrity, then our participants may feel distrusting of others. Therefore, we had to take responsibility for our actions to ensure they did not sabotage future research in the BCI field and with individuals who have CP.

Conclusion
Researching novel forms of assistive technology for individuals with severe physical disabilities through a participatory and inclusive approach is critically important for the development and design process. This paper examined how doing so can pose a number of ethical and practical issues, and how our research team addressed these issues. Through open discussion and collaboration with other researchers in similar fields, it will be possible to discover a means towards better ways of tackling such issues, that may result in more valuable, reliable and valid participatory research opportunities.

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