

THESIS

INCREASING BCI USABILITY IN THE HOME: ASSESSING THE USER AND
CAREGIVER PERSPECTIVES

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ABSTRACT

INCREASING BCI USABILITY IN THE HOME: ASSESSING THE USER AND CAREGIVER PERSPECTIVES

Objective. Despite research indicating that brain-computer interface (BCI) technology can be an effective option for persons with motor disabilities, BCI is currently not being used by this population on a regular basis. The purpose of this research is to determine the current usability of the BCI system in the user's home from the perspective of BCI users with motor disabilities and their caregivers in order to influence the future direction of BCI advancement to improve the usability of BCI technology for this population. **Method.** Within this study, there were four separate phases. In Phase 1, using feedback from five participants with motor disabilities and three caregivers for persons with motor disabilities, a questionnaire was developed for both BCI users and caregivers to assess the experience of setting up and using the BCI system. In Phase 2, these questionnaires were administered to five participants with motor disabilities and their caregivers a total of three times after experiencing the set-up and use of a P300 BCI system in the user's home on three separate occasions. In Phase 3, the responses of the questionnaires were analyzed and common themes and patterns were used to develop a list of questions to guide a focus group discussion. Finally, in Phase 4 a focus group consisting of three BCI users and two caregivers was held to gather more in depth information about the experience of using and setting up the BCI system. Throughout these phases, both quantitative and qualitative methods were used to analyze data. **Results:** Quantitative data analysis of questionnaire responses yielded no significant results; however, a variety of patterns were

identified and within these patterns multiple patterns were found to approach significance. Relationships that approached significance included the difference between user and caregiver ratings for ease of use over time ($z = -1.730, p = 0.084$) and the difference between user and caregiver ratings for the likelihood of using or advocating for the use of BCI in the home on a regular basis ($z = -1.792, p = 0.073$). These findings showed that ease of use decreased across the course of the three visits for both caregivers and users and that caregivers were more likely to advocate for the use of BCI on a regular basis than BCI users. When asked what area of life participants wanted this version and future versions of BCI to help increase users' current participation, the most common response chosen by users was environmental aids to daily living (EADL) while the most common response for caregivers was verbal and written communication. Qualitative analysis of the focus group provided answers to the three research questions (What are current barriers preventing BCI from being used by persons with disabilities on a regular basis in the home?; What are the aspects of BCI that BCI user's and caregivers enjoy?; And what are BCI users' and their caregivers' desires for the future of BCI) and yielded three emergent themes: the cost benefit analysis of BCI use, comparison of BCI to existing technology, and BCI and its relationship to independence. **Conclusions.** Although at its current state, none of the participants believed that the P300 BCI system would be a valuable addition to their life, users and caregivers agreed that in cases where the need was great enough, the challenges of using the system would be outweighed by its benefits. With the implementation of developments that decrease the challenges involved in setting up and using the system or the implementation of developments that increase the utility of real life applications, future BCI systems will become more practical options for a larger population.

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INTRODUCTION

Brain-Computer Interface Technology

A brain-computer interface (BCI) is a system that measures activity in the central nervous system (CNS) and converts these brain signals into artificial outputs that can be used to replace, restore, enhance, supplement, or improve natural CNS activity; therefore, changing the interaction that the CNS has with its environment (Wolpaw & Wolpaw, 2012). More simply, BCI can be explained as a system that translates “brain signals into new kinds of outputs” (Wolpaw & Wolpaw, 2012). At present, there are two major ways in which BCI technology can be applied to aid persons with motor disabilities who require the assistance of a caregiver or assistive technology for daily functioning (Daly & Huggins, 2015; Daly & Wolpaw, 2008). The first strategy uses brain signals to allow the user to engage the BCI output for communication or device control through manipulating aspects of the environment such as a light switch, thermostat, power wheelchair, or communication device. The second use of BCI involves using the system as a motor-learning assist device to enhance motor control recovery by guiding activation or deactivation of brain signals to restore normal CNS functioning in persons with cognitive impairment or pathology (Daly & Wolpaw, 2008). Although both applications present great potential for persons with disabilities, for the purpose of this study, we have chosen to focus on BCI application in environmental control, an area of BCI that has been the focus of a considerable body of research (Daly & Wolpaw, 2008). In assistive technology literature, there are a variety of terms that describe the use of technology to control aspects of the environment including both “electronic aids to daily living” (EADL) and “electronic control units” (ECU). In this document, the term EADL will be used to describe this area of BCI use.

For persons with motor disabilities such as spinal cord injury (SCI), cerebral palsy (CP), stroke, multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS), the communication channels that these individuals use to interact with the environment have often been damaged, causing partial or complete loss of voluntary muscle activities, including the ability to communicate and participate in meaningful activity (Bamdad, Zarshenas, & Auais, 2015). Because BCI offers an alternative way for these individuals to interact with their surroundings, the use of BCI technology for EADL use presents notable potential for this population to be used as a tool to control mobility, communication, and improve quality of life through converting patterns of brain activity into usable control commands for external devices (Bamdad et al., 2015). In addition, because these systems do not rely on neuromuscular activity, BCIs have been reported to remain a viable form of assistive technology after eye-tracking systems fail (Sellers, Vaughan, & Wolpaw, 2010; Holz, Botrel, Kaufmann, & Kübler, 2015). For this same reason, BCI systems can also be used in situations where voice recognition software or scanning and switch systems are unable to be used due to a lack of muscle function. Based on these findings, it can be suggested that BCI is currently the only viable option for restoring both communication and autonomy in severely disabled populations (Kübler, Holz, Sellers, & Vaughan, 2015).

In order to detect brain activity to convert to usable outputs, both invasive and non-invasive methods of signal acquisition can be used. Invasive signal acquisition entails implanting electrodes under the scalp while non-invasive techniques can include a variety of methods that detect factors such as blood volume, cerebral metabolism, magnetic activity, blood glucose, or electric activity through external methods such as functional magnetic resonance imaging (fMRI), near infrared spectroscopy (NIRS), magnetoencephalography (MEG), positron emission tomography (PET), or electroencephalography (EEG) (Bamdad, Zarshenas, & Auais, 2015). Although invasive

methods have been found to provide better signal quality, due to the need for surgery, the high cost, social stigma, and the potential safety risks that these procedures pose, this method of acquisition has been determined to be impractical for routine use (Bambad et al., 2015). Within non-invasive methods, MEG, fMRI, PET, and NIRS have also been determined to be impractical for daily usage at this stage of development because of their complex technical requirements, high cost, and limited real-time connection capabilities (Bambad et al., 2015). Therefore, based on these limitations, electrical field recording through the scalp using EEG has been identified as the most likely method to be of practical value for clinical use (Bambad et al., 2015; Daly & Wolpaw, 2008). Because of this, within the application of non-invasive EADL systems, we have chosen to concentrate on the use of EEG for signal acquisition for the purpose of this study. Within EEG collection methods, both wireless and wire based systems can be used. Although wireless systems offer increased portability, because wired systems have been proven to be more accurate in research, a wire based system was used in the present study (Tello, Müller, Bastos-Filho, & Ferreira, 2014).

Once brain activity has been detected, algorithms are used to translate patterns of activity into usable signals (Wolpaw & Wolpaw, 2012). In BCI systems, the data collected from signal acquisition can be used either online for immediate applications or offline to develop and fine tune these algorithms (McFarland & Krusienski, 2012). In an online system, the BCI user's brain activity is translated to usable outputs in real time allowing the user to control the BCI system and see immediate results of their brain activity. In offline systems, brain activity is collected from users and then evaluated after the event in a lab or home setting. Because online systems allow users to utilize the system in real time and allow developers to test the how their algorithms perform in real life applications, this form of BCI is optimal for research focusing on the end user

experience, while offline research is valuable for optimizing algorithms for future application. (McFarland & Krusienski, 2012). For the purpose of this study, both online and offline data analysis was used to allow users and caregivers to experience the technology in real time while also providing the opportunity for further analysis to better improve and fine tune the technology.

BCI Use For Persons with Disabilities

Because of the great potential that BCI technology presents for persons with motor disabilities, over the past 20 years, the field of BCI has grown exponentially (Kübler et al., 2015). In fact, according to Wolpaw and Wolpaw (2012), persons with disabilities are the “principal reason for the existence of the field and for the substantial attention and support it currently receives” (p. 10). Recent studies have demonstrated that fast and reliable control of BCI systems is possible; however, to date, the majority of research has focused on offline analysis and the majority of participants have consisted of healthy participants in a lab setting (Kübler et al., 2015). In fact, according to a scoping review conducted by Bamdad et al., (2015), based on the papers summarized relating to BCI in rehabilitation, 70% of BCI studies to date focus on theoretical research while only 30% include experimental results with a practical BCI system. Furthermore, within the research focusing on practical systems, even less of these studies focus on participants with motor disabilities (Bamdad et al., 2015). Although offline studies with healthy populations provide valuable insight into improving signal detection and translation, in order to bridge the gap between research and real-life application, more research focusing on target populations is needed in order to determine BCI utility and reliability for independent use in persons with motor disabilities (Kübler et al., 2015).

BCI Research in Target Populations

Although research in target populations is limited, the results of recent studies with these populations have been promising. One study conducted by Kaufmann, Schulz, Köblitz, Renner, Wessig, and Kübler (2013) found that, although in previous offline studies, participants with neurodegenerative conditions were found to perform significantly lower than healthy participants on BCI tasks using a P300 system, performance was found to increase in an online study with a simple modification where the stimuli was converted to faces. In fact, with this modification, the participants' performance increased to such an extent that it did not differ significantly from the performance of healthy participants. Since that study, a variety of more recent studies have offered additional support for the fact that BCI systems can be used effectively by persons with motor disabilities. So far, the largest study conducted with target populations was completed by McCane et al (2014), who tested 25 participants with ALS using a visual P300 based BCI in the participants' home environment. The results of this study found that the majority of participants were able to use the BCI system for communication despite being severely affected by ALS and that for the participants who were not able to use the system, visual impairment was the principal obstacle (McCane et al., 2014). An additional study published the following year by McCane et al. (2015) found that when comparing the use of a P300-based BCI speller between people severely disabled by ALS and age matched control subjects, communication rate and accuracy did not differ significantly. A final, recent study conducted by Kosmyna, Barnard, Bonnefond, and Rivet (2016) compared performance accuracy, performance time, usability, and feasibility of using a BCI system for EADL between 12 healthy participants and two participants with motor disabilities and found that the participants with disabilities actually achieved a higher accuracy and rated higher scores in ease of learning than the healthy controls. While these limited studies offer strong support

for the use of these systems for persons with motor disabilities, because the majority of these studies are exploratory and focus mostly on ALS and other neurodegenerative disorders, more research is needed to confirm that these findings are consistent and generalizable to other populations.

BCI Research in Target Populations in the Home

In addition to research focusing on target populations, in order to assess BCI utility and reliability in ecologically valid environments, research must also be conducted using these populations in their own homes (Kubler et al., 2015). To date, while there have been promising studies conducted in the homes of persons with motor disabilities, the number of these studies are limited and the majority are either short term studies or are case studies focusing on a single individual. The two previously mentioned studies conducted by McCane et al., (2014) and McCane et al (2015) exploring BCI use in ALS populations both took place in participants' homes with the exception of two participants who completed the study in a hospital setting. In both of these studies, although promising results were found for the efficacy of BCI use in this setting for this population, the studies were short term, where each participant took part in one BCI session lasting 60-90 minutes. Long term studies have also supported the efficacy of BCI use in the home; however, the majority of these studies have focused on a single subject. One study conducted by Sellers, Vaughan, and Wolpaw (2010) investigated the independent home use of non-invasive EEG based BCI system of a man with ALS who was no longer able to use conventional assistive devices. They found that the system was not only usable and stable in the home for over 2.5 years, but it also greatly improved the participants' independence in social interactions and at work, further highlighting the potential that BCI systems can have for improving the quality of life of persons with severe motor impairments (Sellers, et al., 2010). A similar case study conducted by Holz,

Botrel, Kaufmann, and Kübler (2015) found comparable results when evaluating the influence of a P300 BCI-controlled painting application on the quality of life of a 73 year old woman with ALS in a locked-in state. Although the painting application did not increase her independence, after it was used in the home for over 14 months, it was found to have a positive impact on happiness, self-esteem, productivity, performance, quality of life, usefulness, self-confidence, and ability to participate and a negative impact on frustration.

In addition to studies conducted in participants' homes, there has been research conducted in simulated home environments. The previously mentioned study conducted by Kosmyna et al., (2016) which compared performance and satisfaction with BCI systems between healthy participants and participants with motor disabilities attempted to simulate an ecologically valid setting through creating a realistic smart-home environment where participants were able to turn on a light, turn on and stop a tea kettle, lower and raise the blinds, and turn on and off a television. The high accuracy of participants with motor disabilities in this study was postulated to be the result of stronger motivation and focus, which was likely supported by the fact that the BCI system was used in a realistic environment to complete meaningful tasks. Although this study supports claims that BCI can be used successfully by persons with motor disabilities in their homes and that these environments can potentially improve accuracy and satisfaction, more research is needed to confirm that similar results would be found in non-simulated and controlled environments.

BCI Research in User Interest

In addition to these studies implicating the effectiveness that BCI technology can have on target populations in a home setting, multiple studies have also been conducted surrounding the interest that persons within these populations have in using BCI technology to improve functioning. One study conducted by Collinger et al. (2013) evaluated interest among 57 veterans with spinal

cord injury (SCI) using an anonymous survey and determined that over 80% of participants were interested in using a BCI to restore lost function if it did not inconvenience other aspects of their lives. An additional survey of 38 persons with spinal cord injury found that 76% of the participant sample self-identified as being interested in using BCI with the highest interest among the 24 persons who were categorized as low functioning (96%) but still significant interest among the 14 considered to be high functioning (43%) (Huggins, Moinuddin, Chiodo, & Wren, 2015). In a third study conducted at the 2013 International Brain Computer Interface Meeting, a Virtual User's Forum was organized to collect feedback from actual BCI users. This "forum" included data from responses to a survey of expert BCI users, transcripts of interviews with novice BCI users, and prepared statements from two authors who are also BCI users (Peters et al., 2015). Survey respondents were asked about their reasons for trying BCI and about their experiences as participants and the responses indicated that participants appreciated the opportunity to be involved in BCI research. The majority of participants indicated that they were interested in exploring BCI for future personal use or because they had difficulty with other methods of assistive technology (Peters et al., 2015).

BCI Research Focusing on the User Perspective

Based on the aforementioned studies, evidence suggests that, for persons with certain conditions, BCI could be an effective assistive technology option that has shown potential for effectiveness in the home. According to the number of studies that have focused on BCI perceptions, it has also shown to be a technology in which persons with motor disabilities have expressed significant interest. Therefore, taking this information into consideration, why are applications of BCI for persons affected by motor disabilities in the home still limited? In order to answer this question, more research needs to be conducted surrounding the personal experience of

the user. In addition to learning about the accuracy and speed of the system, in order to ensure that systems will actually be used by these populations, more focus must also be applied to the qualitative user experience to determine the changes that are needed to develop a BCI system that is practical and deliverable in the user's natural environment (Blain-Moraes, Schaff, Gruis, Huggins, & Wren, 2012).

This is not to say that research of this type has not been conducted. Peters et al. (2015) directly addressed the user experience by soliciting feedback from persons with disabilities who were both novice and expert BCI users using survey responses, interviews, and statements from BCI users with motor disabilities in the aforementioned study relating to BCI user feedback. In this study, participants indicated a number of current issues with the BCI system including slow typing speed, the mess, inconvenience, and discomfort of wet electrodes, system accuracy, portability, reliability and dependability, complicated set-up for caregivers, and the current cost of BCI. When asked to provide advice for future studies, respondents' suggestions for researchers included making more home visits, "listen[ing] to feedback from actual users," and considering individuals' abilities and preferences when designing and testing BCIs. Finally, participants urged BCI testing with the target population, because healthy users may perform better than people with disabilities (Peters et al., 2015). An additional study conducted by Blain-Moraes et al., (2012) found similar results after conducting a focus group with participants with ALS who had used a p300 BCI system. Participants indicated that in order for BCI systems to be accepted by persons with ALS, "the inconvenience of acquiring signals from the brain needs to be minimized, the interfaces between BCIs and existing technologies need to be provided, and the burden of the technology on the caregiver needs to be minimized" (p. 523). Based on this important feedback, it is clear that while a number of current problems have been identified, more research needs to be

conducted to determine exactly what needs to change within the current BCI set-up and what specific steps need to be taken to make these changes happen.

BCI Research with Caregivers

In addition to the end-user experience, research regarding the experience of caregivers in the process is also important for determining the feasibility of implementing these systems in the homes of the severely impaired. In fact, according to Kubler et al. (2015), “the significant others who support BCI set-up are the most important feature of the end-users’ environment” (p. S30). This is true because despite efforts to make the process as streamlined as possible, at present, end-users cannot yet use the BCI fully independently and this will be true especially in the case of target populations who experience significant motor impairments (Kübler et al., 2015). According to Vaughan et al. (2006), in order to evaluate the ultimate usefulness of BCI, it is necessary to take not only the experience of the user into account but also their family members and caregivers including measurements of satisfaction and quality of life. Although a limited number of studies have included the caregiver’s perspective including Liberati et al. (2015) who used a focus group to evaluate the opinions and requirements of person’s with ALS, their caregivers, and healthcare assistants with regard to developing a BCI system and Blain-Morales et al. (2012) who also conducted a focus group with individuals with ALS and their caregivers to determine the barriers to and mediators of BCI acceptance in this population, more research in this area is needed. No such study has been conducted surrounding the opinions of both BCI users with motor disabilities and their caregivers outside of ALS, no qualitative studies have explored the opinions of BCI users who have used the system in their own homes, and no study has evaluated the perspective of caregivers who have set up and implemented the system themselves.

PURPOSE

Taking the above information into consideration, the purpose of this study is to determine the current usability of the BCI system in the user's home from the perspective of BCI users with motor disabilities and their caregivers in order to influence the future direction of BCI advancement to improve the usability of BCI technology for this population.

RESEARCH QUESTIONS

Question 1: What are the current barriers preventing BCI from being used by persons with disabilities on a regular basis in the home?

Question 2: What are the aspects of BCI that BCI users and their caregivers enjoy?

Question 3: What are BCI users' and their caregivers' desires for the future of BCI?

METHODS

Participants

In total, fourteen participants were recruited successfully for the study. Out of these participants, eight were affected by motor disabilities resulting from stroke, traumatic brain injury (TBI), CP, MS, and SCI. These eight individuals were recruited to represent the perspective of BCI “users.” Three of these participants had experience with BCI from participating in a past study. In addition to the user group, six other participants, who either were caregivers for these individuals or provided care for someone currently experiencing significant motor disability, agreed to participate in this study. These six participants were recruited to represent the perspective of “caregivers.”

Recruitment for both users and caregivers occurred through contacting participants of past BCI studies at CSU with the assistance of the Center for Assistive Technology and through the distribution of institutional review board (IRB) approved flyers at a variety of community exercise classes offered by the City of Fort Collins Adaptive Recreation Opportunities Program. After the flyers were distributed, a member of the research team visited these classes to speak about the project and answer any questions. Inclusion criteria for the eight BCI users included: age range from 26-65, ability to speak English, normal or corrected vision and hearing, and the presence of a motor disability requiring the assistance of an assistive device or caregiver to complete all necessary activities of daily living. Participants were not included as BCI users in the study if they had a history of fainting, if the individual had medical precautions against activities requiring movement of the head and neck, sitting for extended periods of time, or computer use. Inclusion criteria for the six caregivers included: age range above 18, ability to

speak English, and the presence of normal or corrected vision and hearing. All participants and caregivers completed written consent forms indicating voluntary participation.

Within this study, there were four separate phases. In Phase 1, a questionnaire was developed for both users and caregivers to assess the experience of setting up and using the BCI system. In Phase 2, these questionnaires were administered to participants after using the BCI system in their homes. In Phase 3, the responses of the questionnaires were analyzed and common themes and patterns were used to develop a list of questions to guide a focus group discussion. Finally, in Phase 4 a focus group was held to gather more in depth information about the experience of using and setting up the BCI system. Out of these four phases, participants took part in Phase 1, 2, and 4. For each phase, different groupings of individuals participated, based on availability. While some participants were able to participate in all three phases, some were only able to participate in one or two of the three phases. For Phase 1, five users and three caregivers were recruited indicating a total of eight participants. For Phase 2, five users and their five caregivers were recruited indicating a total of ten participants. For Phase 4, three BCI users and two caregivers were recruited. A description of participant demographics and the phases that each participant took part in is provided in Table 1 for users and Table 2 for caregivers below.

Table 1: Participant Demographics for Users

<i>Subject</i>	<i>Age (Years)</i>	<i>Gender</i>	<i>Diagnosis</i>	<i>Experience with BCI</i>	<i>Phase Participated</i>
U1	57	F	Stroke	N	1, 2
U2	29	M	Quadriplegia	Y	1, 2, 4
U3	26	M	Traumatic Brain Injury	N	2, 4
U4	39	M	Cerebral Palsy	N	2, 4
U5	59	F	Multiple Sclerosis	N	2
U6	NR	M	Quadriplegia	Y	1
U7	NR	M	Quadriplegia	N	1
U8	NR	F	Multiple Sclerosis	Y	1

NR: Not Requested

Table 2: Participant Demographics for Caregivers

<i>Subject</i>	<i>Age (Years)</i>	<i>Gender</i>	<i>Relationship to User</i>	<i>Experience with BCI</i>	<i>Phase Participated</i>
C1	NR	M	Husband of U1	N	1, 2
C2	NR	F	Girlfriend of U2	N	1, 2, 4
C3	NR	F	Mother of U3	N	2, 4
C4	NR	F	Friend of U4	N	2
C5	NR	F	Hired caregiver for U5	N	2, 4
C6	NR	F	Hired caregiver for woman who could not participate in the study	N	1

NR: Not Requested

PROCEDURES

Data Collection

Phase 1: Development of Questionnaires

Using the Tools for Brain-Computer Interaction (TOBI) short questionnaire for end users, the Matching Person and Technology (MPT) assessment and the Colorado State University (CSU) BCI Questionnaire for End-Users, a questionnaire developed for a previous BCI study at CSU, two separate questionnaires relating to the experience of using and setting up the BCI system were created: one questionnaire for end users and one for caregivers. A new questionnaire was created instead of utilizing a previously existing option because the present study aimed to capture information about both the experience of using and setting up the technology and the users' and caregivers' dreams for the future of BCI. Aspects relating to the user and caregiver experience of using the technology were drawn from the CSU BCI Questionnaire for End-Users and aspects relating to the participants' future desires for BCI were drawn from the TOBI short questionnaire and the MPT assessment. Because these assessments all focused on end-users of technology, they were also modified to include the perspective of caregivers in the caregiver questionnaire.

The questionnaires consisted of Likert scale, multiple choice, and open-ended questions in order to collect a broad range of data. These questionnaires were assessed for quality through member checking in the form of sending the user questionnaire to five potential BCI users with motor disabilities and the caregiver questionnaire to three caregivers of BCI users. A follow up phone call was then conducted to discuss impressions and determine potential changes. Changes in the questionnaire that resulted from these discussions included providing a simplified definition of BCI technology, simplifying questions to make them more easily understood, adding an "other"

section to allow participants to come up with additional answers if needed, and including more opportunities for explanation of answers. Through this process, the final questionnaires used in the study were developed. For reference, a copy of the final user questionnaire is provided in Appendix A and a copy of the final caregiver questionnaire is provided in Appendix B.

Phase 2: Administration of Questionnaire in the Home

Once the questionnaires were finalized, they were administered to five user-caregiver dyads after experiencing the BCI technology in their own homes. During this phase, the CSU BCI team visited each home three times and each visit lasted approximately two hours. During each session, a 64 channel, wet electrode BCI system was brought to the user's home and the system was set up in the user's natural environment. For each visit, the Colorado Electroencephalography and Brain-Computer Interfaces Laboratory (CEBL3; <http://www.cs.colostate.edu/eeg/main/software/cebl3>) interface was used with a BioSemi system which acquired EEG signals. Set up of the system included positioning the user and BCI system in an open space, applying the EEG cap to the user, filling an applicator with gel, using this applicator to insert a small amount of gel into 64 small spaces in the cap, and finally plugging in 64 electrodes into each of these spaces by matching the electrode number with the labels listed on the cap.

After the system was set up, the user participated in one of two BCI exercises on separate days: the P300 speller or mental tasks exercise. Each exercise represented a different approach to BCI for EADL use. The P300 speller exercise used event related potentials (ERPs) to convert activity in the brain into usable outputs while the mental tasks exercise relied on reading electrical activity patterns in the brain. The P300 speller approach was used in the first and third sessions while the mental tasks application was used during the second session. The P300 speller

application allowed users to spell words through directing visual attention to individual letters on a screen by counting the number of times the desired letter flashed. For this exercise, users were first asked to spell a number of prepared words and were then offered a chance to complete a free spelling activity. The mental tasks application prompted users to control an arrow on the screen using different mental exercises. For example, the user was prompted to imagine moving his or her left arm to make the arrow point to the left, or to imagine singing his or her favorite song to cause the arrow to move upward.

Caregivers remained involved throughout the process through observing and assisting in the set-up of the system. During the first session, the caregiver was instructed to observe the research team setting up the system. During the second session, the caregiver was invited to assist the lab members in setting up the system. For the third and final session, the caregiver was prompted to independently complete as much of the process as he or she was comfortable with, with assistance from lab members available, if needed. After each session, both the caregiver and the user were separately administered either the caregiver or user questionnaire relating to the experience of using and setting up the system. The questionnaires were administered verbally and the answers were transcribed by a research team member. This method was used for each user and caregiver with the exception of one user who preferred to write the answers independently. For consistency, the same research team member administered the user questionnaire during each visit except for one occasion when that specific research team member was not available to attend the session. On the other hand, for caregivers, the research team member administering the caregiver questionnaire was different from session to session depending on which team member was available to attend each session. Because the questionnaire was administered during each session, the caregiver and

the user each completed the same questionnaire three times yielding 30 total completed questionnaires – 15 caregiver questionnaires and 15 user questionnaires.

Phase 3: Analysis of Questionnaire Responses

Because the questionnaires consisted of Likert scale, multiple choice, and open-ended questions, both quantitative and qualitative analyses were used to analyze responses in order to shape focus group discussion. For quantitative analysis, the responses to all Likert scale and multiple choice questions were recorded and the responses were compared between all ten participants and analyzed for patterns. For qualitative analysis, repeated concepts mentioned in the comments section of questions were separated into themes. Using the patterns found in the Likert scale and multiple choice questions and the themes found in the open-ended responses, the researcher created 11 questions, which served to break down the three research questions of the study into smaller, more detailed parts. These 11 questions then were used to guide the focus group discussion in Phase 4 in order to gain more targeted and complete information based on participant responses on the questionnaires.

One example of quantitative analysis shaping the focus group questions is explained in the following case: The responses to the multiple-choice question “In which area of your life would you use this version of BCI technology to increase your (or the user’s) participation” were counted and the most commonly selected answers were noted for both caregivers and users. Using this information, the following focus group question was created: “When asked what area of life you think BCI could help increase participation, the most commonly selected area for users was EADL use and for caregivers was verbal and written communication. What would this look like in a real-life context?”

An example of a question influenced by qualitative analysis was “For using the BCI system, the most common areas of difficulty mentioned in the questionnaire were: comfort, limited mobility, system accuracy, the need for gel, the presence of wires, and the level of concentration required. Which of these do you believe was the most significant barrier? Do you have any ideas for solutions to these barriers?” This question was created after participant comments were analyzed from the open-ended question “What did you not like about this technology and why?” and repeated themes were noted from comments such as “eliminate the gel and all the hanging wires and it would be perfect” or “The gel is not great. If I were to go to work after this, I wouldn’t want sticky gel in my hair;” and “concentrating on the letters is not something I would want to do all day.” Additional comments about the positive aspects of the system such as: “I believe it would give me more independence. I wouldn’t need my caregiver to do everything for me. I would get to do the work when I wanted to;” “I could control other home environments along with my computer which would allow me to better access the community;” and “It leads to more independence which leads to overall better quality of life. When using BCI, you get to be human like you don’t have a disability,” led to probing questions in the focus group list such as “how would the uses of BCI we discussed help you in your life?” in order to gain more information about the specific connection between BCI and quality of life.

Phase 4: Focus Group

After the analysis of questionnaire responses was completed and the focus group questions were finalized, a one hour focus group was held in the CSU occupational therapy building. Participants in this phase consisted of a combination of BCI users and caregivers representing four of the five user/ caregiver dyads. Using the 11 open-ended questions developed from participant questionnaire responses, an open discussion was facilitated and audio recorded in order to gain

more in depth insight about the experience using and setting up the BCI system. During this discussion, answers to the focus group questions were outlined on a large note pad so that participants could see that their responses were being interpreted correctly and so that other participants could build their responses off of other's ideas. In order to ensure that each participants' views were included, the focus group facilitator guided the discussion by calling participants' names to ensure that all members participated equally in the discussion.

The content of the focus group was transcribed fully, using an audio recording of the session. Using qualitative techniques such as basic content analysis and theme identification techniques, the content of the transcript was then coded and separated into topics based on repeated content patterns. This process was completed by two researchers for the purpose of analyst triangulation and the resulting topics were compared and discussed (Creswell, 2013, p. 251). Common topics selected by both researchers were then combined and formed into final themes. For example, for the theme "cost-benefit analysis of BCI" use, two commonly discussed topics were separated into codes for both the "challenges" and "benefits" of BCI use. After comparing and discussing these codes, both researchers agreed that these codes could be combined to form the final theme. The theme "comparison of BCI to existing technology" was created after it was discovered that both researchers created a code for "technology" by grouping all participant quotes surrounding the discussion of assistive technology into one group. After looking closer into these quotations, both researchers agreed that the common theme among the quotes was the relation between these different forms of assistive technology and BCI. From this discussion emerged the final theme.

In addition to uncovering emergent themes, the focus group transcript was also analyzed separately to answer the three research questions of the study: What are the participants' views on

the current barriers to BCI use in the home for persons with disabilities?; What are the parts of BCI that participants enjoyed?; And what are the participants' future desires for BCI technology? For this process, two researchers separately coded the transcript according to these three topic areas. After comparing and discussing the content applied to each research question, common content was decided upon and grouped into the final responses to the three questions. The responses to the three research questions along with a detailed description of the three emergent themes will both be presented separately in the results section.

Quantitative Analysis of Questionnaire Responses

Along with shaping the focus group discussion, responses from the questionnaires were analyzed quantitatively. The data from the 30 questionnaires were used to compare responses between caregivers and users, to look at overall trends for both groups, and to look at any changes in responses across the course of the three home visits. Because of the small number of participants, non-parametric tests were used to analyze these comparisons due to the lack of normal distribution of responses. Wilcoxon signed ranks tests were used to compare changes in each group over time (within comparisons) while the Mann-Whitney *U* Test was used to compare differences between groups. For questions 6 and 7 on the user questionnaire and questions 5 and 6 on the caregiver questionnaire, the number of times each response was chosen by participants was calculated and these answers were compared between users and caregivers. For these questions, because of the similarity between the responses “verbal or written communication” and “expression of thoughts/ opinions/ ideas” these two responses were combined into the category “verbal or written communication.”

RESULTS

Questionnaire Data Results

Based on quantitative analysis of the questionnaire responses, neither the Wilcoxon nor the Mann-Whitney U tests yielded significant results. However, despite the lack of significance, a variety of patterns were identified and within these patterns multiple comparisons were found to approach significance. These comparisons will be explained in detail below. For a visual reference, the responses to relevant, questionnaire questions will be presented in bar graph form. The mean user responses to questionnaire questions 1, 2, and 5 for session 1 and session 3 are displayed in Figure 1 (also see Appendix A for the wording of the questions). The mean caregiver responses to questions 1, 2, and 4 for session 1 and session 3 are displayed in Figure 2 (also see Appendix B for the wording of the questions). Finally, the mean group responses for all participants for the same questions for session 1 and session 3 are displayed in Figure 3.

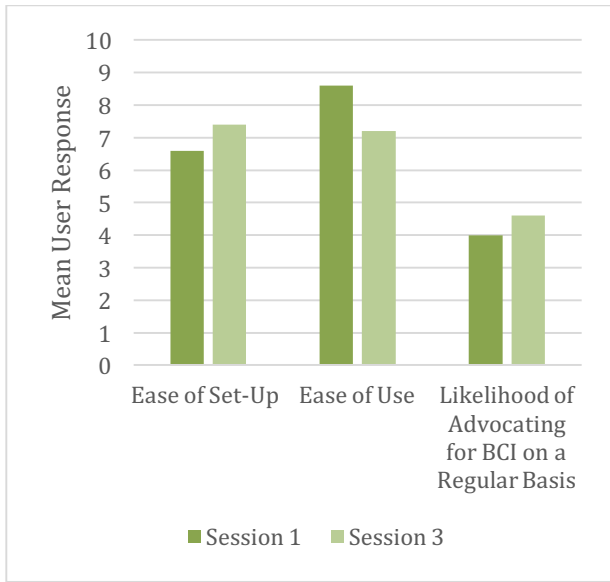


Figure 1: Mean Group User Responses Over Time

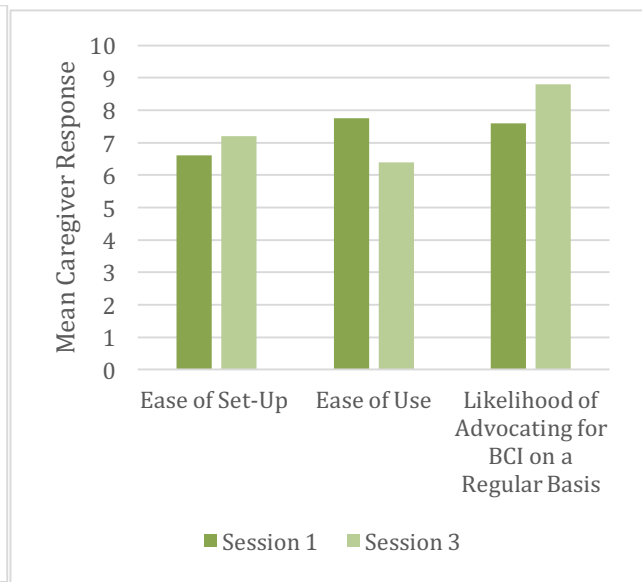


Figure 2: Mean Group Caregiver Responses Over Time

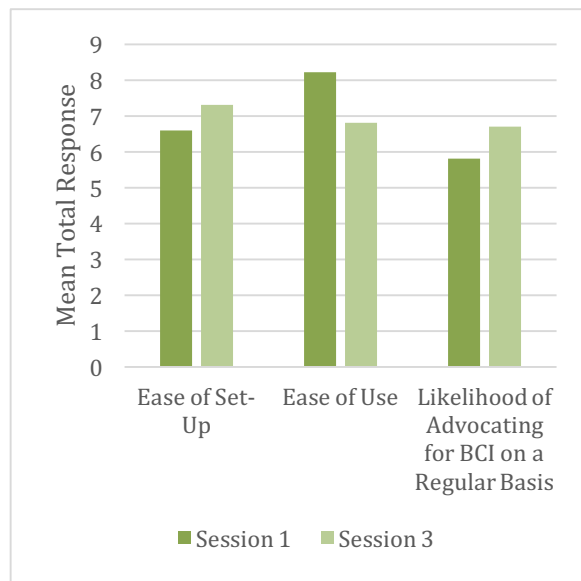


Figure 3: Mean Group Total Responses Over Time

After analysis, one comparison that was found to approach significance was the comparison between user and caregiver ratings for “ease of use” of the BCI system over time. For this question, both users and caregivers were asked to rate their experience using this technology in terms of usability. Participants were asked to choose a number between one and ten with one indicating that the system was extremely difficult to use and ten indicating that there were no issues with use. For this comparison, a Wilcoxon test was conducted to determine whether all participants’ ratings and the results approached a significant change over time, $z = -1.730, p = 0.084$. For this comparison, the mean of ranks for session 1 was 6 while the mean of ranks for session 3 was 4. Therefore, according to questionnaire responses, both caregivers’ and users’ ratings decreased steadily across the course of the 3 visits indicating that each group rated that the system became more difficult to use over time (See Figure 3).

Although the remaining comparisons looking at changes within groups over time were determined to be insignificant, a variety of patterns were found. For set-up of the system, ratings increased from session 1 to session 3, although not significantly, indicating that both users and caregivers rated the set-up of the system to be easier over time ($z = -0.846, p = 0.397$). For advocating for BCI use on a regular basis, both user and caregiver ratings increased from session 1 to session 3, although not significantly, indicating that all participants rated themselves as being more likely to advocate for BCI use over the course of the three sessions ($z = -0.916, p = 0.36$). For users, the number of hours per day this group said they would be able to use the system comfortably increased from session 1 to session 3 ($z = -0.707, p = 0.480$) though, interestingly, user ratings for comfort decreased from session 1 to session 3, although not significantly ($z = -0.816, p = 0.414$). The mean group user responses for questionnaire questions 3 and 4 relating to comfort are displayed in Figure 4 below.

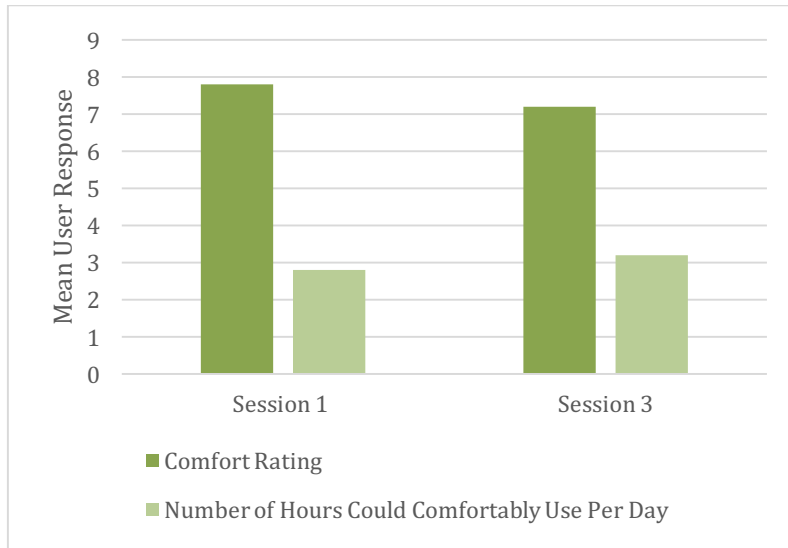


Figure 4: Comfort Over Time

For comparisons between groups, another pattern that approached significance was the difference between caregivers' and users' ratings for BCI advocacy. For this question, both caregivers and users were asked to rate the likelihood that they would use or advocate for the use of BCI technology in the home on a regular basis on a scale of one to ten with a one meaning "not at all likely" and ten meaning "definitely likely." For this comparison, a Mann-Whitney *U* test was conducted to evaluate the difference in responses for this question between users and caregivers during the third session, or the final home visit. The results of the test were found to approach significance, $z = -1.792$, $p = 0.073$ with caregivers having a mean rank of 7.2 and users having a mean rank of 3.8 indicating that caregivers rated themselves as being much more likely to advocate for the use of this type of assistive technology on a regular basis. In sessions one and two, caregivers also scored higher than users, but the results of the Mann-Whitney *U* test did not approach significance.

For the multiple-choice questions relating to participant opinions about real-life applications of BCI systems, responses varied between users and caregivers, but for both groups

the most commonly selected areas where participants believed that BCI could help to increase participation were EADL use and verbal and written communication. For the question: “in which area of your life would you use this version of BCI technology to increase your current participation” or for caregivers, “In which area of life do you believe this version of BCI technology could help increase the users’ current participation?” the most commonly selected answer for users was EADL while the most commonly selected answer for caregivers was verbal or written communication. For this question, the most commonly selected answer for both users and caregivers collectively was verbal or written communication (see Figure 5). For the question: “In which area of your life would you want BCI technology to increase your current participation?” and for caregivers “In which area of life do you believe future BCI technology has potential to help increase the user’s participation?” again, users more commonly selected EADL while caregivers more commonly selected verbal or written communication. One difference, however, was that for this question, the most commonly selected answer for both groups collectively was EADL (See Figure 6).

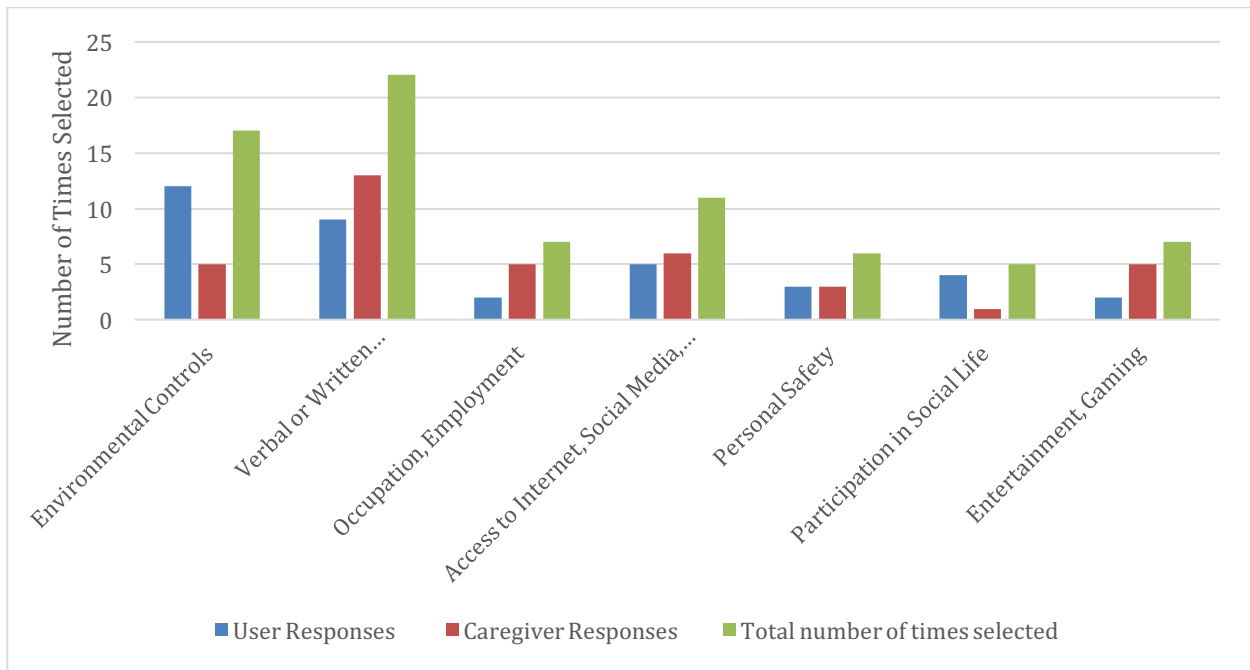


Figure 5: Participant Responses to "In which area of your life would you use *this version* of BCI technology to increase your current participation?"

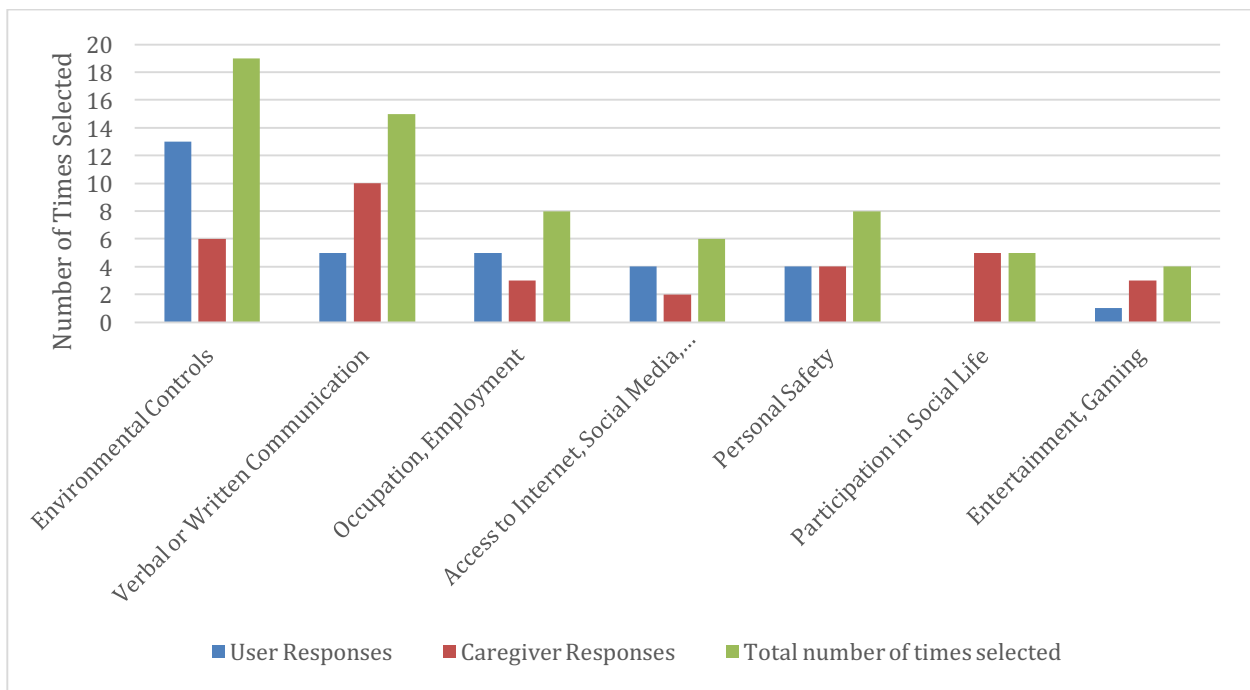


Figure 6: Participant Responses to "In which area of your life would you want BCI technology to increase your current participation?"

Focus Group Results

Throughout the focus group, the three research questions of this study remained a guiding force in the discussion: What are the current barriers preventing BCI from being used by persons with disabilities on a regular basis in the home? What are the aspects of BCI that BCI users and their caregivers enjoy? And what are BCI users' and their caregivers' desires for the future of BCI? Due to this organization of the focus group around the study questions, valuable responses to these questions were provided by participants, which helped to gain more detailed information about the topics addressed in the questionnaire. In addition to these responses, however, three common themes were found to re-emerge continually throughout the discussion: the cost benefit analysis of BCI use, the comparison of BCI to existing technology, and BCI and its relationship to independence. These themes represented the shared meaning of the experience of using and setting up the BCI system for both BCI users and their caregivers. Below, the responses to the three research questions are outlined followed by a detailed explanation of the three common themes.

Answers to Research Questions

Research Question 1: What are the current barriers preventing BCI from being used by persons with disabilities on a regular basis in the home?

For barriers, a variety of different ideas were presented for challenges relating to both the set-up and use of the BCI system. When asked about the most important barriers to using BCI, the participants agreed that comfort and limited mobility were the two most significant factors. This response aligns with the ratings that users selected for comfort on the questionnaire and could explain why these scores actually decreased over the course of the 3 sessions (Refer again to Figure 4). For comfort, one user explained “it feels like a really tight swim cap and your brain

feels like it's going to swell." For mobility, a caregiver said, "I know for (user), she wouldn't really use it because you have to stay in the same place because of the wires and you can't really move around." Another user said, "I worried about the wires popping out." In addition to comfort and mobility, for use of BCI, other commonly-mentioned barriers included the use of gel with the electrodes, the physical appearance of the system, the cost, and the accuracy of the online classification of the BCI system.

Within the topic of accuracy, one important concern that was brought up by participants was the fact that many common characteristics of conditions such as TBI, MS, or CP can contribute to decreased accuracy of the system. For example, one user mentioned "I felt that I was less accurate when I was tired. Like I thought I had more trouble with accuracy after I had worked all day versus when I hadn't worked before." A caregiver then added "And sleep is always an issue with brain injury, well from my experience with brain injury, so that might always be a problem." A similar conversation occurred relating to a user with MS. After discussing how deep concentration is required to operate the system and how frustration can decrease concentration, a caregiver mentioned "And I feel that (user) gets frustrated in general because she just isn't able to do the things that she used to be able to do, so I think frustration is probably something that happens a lot." In both of these situations, users and caregivers expressed how commonly experienced side effects of certain motor conditions can actually make the BCI system more difficult to use. These opinions could explain why both user and caregiver ratings for ease of use of the system decreased over the course of the three sessions.

For set-up of the BCI system, commonly mentioned barriers included the complicated nature of the system, the time the system takes to set up, the uncertainty surrounding how much gel to apply, and the small size of the labels on the electrodes which one caregiver had difficulty

reading due to low vision. One caregiver explained that the process of setting up the BCI was “a little intimidating because of all the machines,” while another commented, “I just thought that it wasn’t user friendly. Took way too much set-up.”

Finally, for barriers to BCI use in the home, participants indicated that distractions, the interference of 60hz, and the number of people required to set up the system were major challenges. One caregiver mentioned that “(user’s) granddaughter was yelling on the phone and distracting her in that way” and that “(user) got a little flustered and upset with her granddaughter and so she thought that that really affected her concentration and her ability to use the program.” For 60hz interference, one user mentioned that in order to use the system, the research team had to turn off his internet in order to avoid picking up interfering signals. He explained “Yeah and that was a huge part because I didn’t have internet and I need internet!”

Research Question 2: What are the aspects of BCI that BCI users and their caregivers enjoy?

For the aspects of the current BCI system that users and caregivers enjoyed, the list was shorter but valuable. Participants appreciated that the system did not require the user’s voice and that it enabled users to spell words or control arrows on a computer screen using their mind: “For me, to be able think about what I wanted to say instead of having to speak was great.” They appreciated that setting up the system seemed to improve with practice, which aligned with the fact that both user and caregiver scores for ease of set-up improved over the course of the three sessions (See Figure 1, 2, and 3) “I think it would just take practice. Like, the faster you would get at putting the gel in. After a while, you’d know how much gel to use so it is just getting used to setting it up.”

Users and caregivers enjoyed the ability to customize aspects of the software to the user. One caregiver mentioned that for the mental tasks BCI exercise, “with (user) we changed some of the mental tasks to make it easier” which she felt was important because “I know (user) said she had trouble with the spinning cube one.” Finally, users and caregivers agreed that the software was intuitive. When asked if any aspect of the software could be changed to make the two BCI exercises easier to understand, one user explained: “overall it made sense to me!”

Research Question 3: What are BCI users’ and their caregivers’ desires for the future of BCI?

Based on the participants’ ideas surrounding the barriers and positive aspects of BCI, a variety of ideas for the future of BCI were suggested. In order to eliminate the barriers of comfort and mobility, participants suggested that in the future, BCI systems could reduce the number of wires needed, through making the system compatible with a system such as *Bluetooth*. One user suggested “even if the wires were bundled together into one wire, that might be easier.” For improving comfort and physical appearance, participants suggested reducing the number of electrodes and creating a cap that is more lightweight and less attention-drawing. One user suggested “you could just have something that is more stylish or something that is more like, uh, headphones” and another user added “like a normal hat!” Participants also suggested options for reducing the inconvenience of applying gel through creating a cap that does not require gel or through creating a simpler system that tells the caregiver if there is enough gel in the cap. For the set-up of the BCI, it was suggested that a more streamlined system should be created to educate caregivers on how to get the system running independently. Ideas for this included the creation of a manual, training video, or one caregiver suggested, “maybe instead of instructions, have

someone come in to train the caregiver on how to use the system or host a training class so they can practice and learn how to do it before having to do it on their own.”

Throughout the focus group discussion, users and caregivers also had a variety of ideas how BCI could be implemented in real life to improve functioning. For written and verbal communication, one of the top priorities of the users and caregivers (see Figures 5 and 6), participants suggested connecting BCI to a phone or computer to “send a text message without saying anything” or to connect to social media. Other suggestions included connecting BCI to computer programs involved in the user’s occupation or employment. One user suggested that BCI should be used in hospitals. “I had a friend who had heart failure and she, um, had a tube going down her throat so she couldn’t talk at all and had to blink to communicate... It would be cool if they could somehow use [BCI] in hospitals. Maybe they could have a screen that allowed people to spell out sentences.” From this suggestion, other participants suggested that BCI be used in nursing homes and rehabilitation facilities for this same purpose. To reduce the time it takes to use the system, one user envisioned that the p300 speller could be engineered to where it allows users to “think of the word instead of thinking of each individual letter for the word.”

For EADL, also a top priority for users and caregivers (see Figures 5 and 6) participants envisioned BCI being used for a variety of uses, including to control music, lamps, faucets, thermostats, open, close and lock doors, change channels on the television, and to control a wheelchair. One caregiver envisioned that BCI could benefit the person that she worked for to get into bed through enabling her to move her bed into a position that allowed her to get onto it safely without assistance.

Emergent Themes

Cost Benefit Analysis of BCI Use

Based on the participants' responses to research question 1, it is apparent that BCI users and caregivers experienced a variety of challenges when setting up and using the BCI system in the home; however, when comparing the positive aspects of BCI use, both users and caregivers expressed that there is a balance between these two aspects and that it is possible for BCI to be a useful tool as long as the benefits are able to outweigh the challenges.

When participants were asked if they would use BCI at its current state in their home on a regular basis, the majority of participants agreed that they would not use the system because the benefits of the BCI did not outweigh the challenges for each of their individual situations. One caregiver said "I know for (user), she wouldn't really use it because of the wires and you can't really move around. If there was a way for it to be wireless or more mobile that would be better." Another user said "I agree with (caregiver). I wish it were Bluetooth and then you could just put it on my head. Then I would probably use it more often." In both of these quotations, although the participants knew that there were benefits to using the system, the inconvenience of being connected to wires led them to believe that the benefits were not worth the immobility caused by the set-up of the system. One thing to note in regard to the issue of wires is the fact that, because this study was also investigating what parameters may best be used for home use, a wired EEG system was used because they have been found to be more accurate than wireless EEG systems (Tello, Müller, Bastos-Filho, & Ferreira, 2014). Because the accuracy of the system would be a factor that participants might take into account when considering the benefits of BCI, if users and caregivers had been more aware of this fact, it might have effected their opinion about the use of wires.

However, when asked if there are populations that exist that could benefit from BCI at its current state, participants expressed that there are certain situations where the benefits would outweigh the current challenges. One user suggested that persons with a progressive form of ALS or populations who are unable to verbalize at all would benefit from using BCI because “the more severe the person’s condition, the more likely someone would be willing to set everything up and use it.” Other suggestions included hospital patients who are in a coma or persons with severe stuttering who are unable to speak. In all of these situations, participants believed that, despite the inconvenience of setting up the system, populations who would truly benefit from the ability to communicate using BCI would still benefit from using the system. Because all of the BCI users who participated in the study were able to speak independently and currently were able to complete necessary tasks with the help of a caregiver or other existing assistive technology options, the benefits of the system were less than for a person who is currently unable to complete these tasks. Because of this, the challenges were more easily able to outweigh these benefits.

The concept of cost-benefit analysis emerged again when discussing how the BCI approaches used in the study could be implemented into real-life situations to benefit users. One caregiver mentioned that the person that she provides care for would likely use the system for long periods in the evening before going to bed. “I could see her maybe using it for times when she doesn’t have to be out in public and she would be wearing it for eight hours or so rather than just one hour at a time, [in order to avoid] having to put in all the gel and having to take it out.” In this situation, the caregiver suggested a scenario where the challenges of setting up and using the system could be minimized in order to make these challenges worth the benefits.

Therefore, based on participants' views relating to the cost-benefit analysis of BCI use, even though the majority of users and caregivers did not see the current system as being a useful addition to their life at this point, participants did believe that the current system could be useful for populations with lower levels of functioning. In addition, participants believed that future BCI systems could one day be beneficial in their specific situations if either the benefits of using the system were increased or the challenges of setting up and using the system were minimized. This idea of cost-benefit could have influenced the fact that while ratings for comfort decreased over the course of the three sessions, the number of hours participants believed they could use BCI in a day increased (See Figure 4). Judging from the fact that scores for advocating for BCI use on a regular basis improved over the course of time (see Figure 1), it is possible that as participants' understanding of the benefits of BCI increased, the benefits began to better outweigh the discomfort.

Comparison of BCI to Existing Technology

In addition to the concept of cost-benefit analysis, another theme that continually emerged during the focus group discussion was the comparison of BCI to other current assistive technology options. Using these comparisons, participants were able to develop ideas for future BCI applications and envision the possibilities for BCI advancement with the use of targeted research and development.

When discussing potential ways that BCI could be implemented into daily life to facilitate EADL, one user positively compared the capabilities of BCI to two existing voice-recognition computer applications he currently uses to complete necessary tasks at home through manipulating aspects of this environment. "For someone like me, I use Google Home and Alexa and through the internet I can do a lot of casting and I can talk to my lamps, I can talk to my

front door, to my TV, I can change channels, talk to my garage door opener, get outside...” Using this example, he envisioned a situation where a BCI system could complete these same tasks using thoughts instead of voice controls. “Yeah like turning on the kitchen lights. I can think about it and ‘click’ they will turn on.” For this participant, being able to control devices without using voice commands would be a particularly valuable feature because of his specific situation. “For me, having a spinal cord injury and no left lung, I run out of breath pretty fast, so for me to be able to think about what I wanted instead of having to speak, that was great.” Based on this quality of BCI, this participant envisioned how BCI, if connected to similar outputs, could one day become an even more valuable system for him than the other related technologies.

In addition to comparisons to voice recognition systems, multiple participants indicated similarities between BCI and a voice-to-text speech recognition software for computer use. The same participant who spoke about the comparison between BCI and voice recognition software said, “I thought [BCI] was a great alternative for me. Instead of using Dragon (Naturally Speaking), I could actually think about what words I wanted to say.” Multiple participants also compared BCI to existing voice to text speech recognition software as a way to envision where the future of BCI potentially could lead. “Honestly I remember when Dragon first came out and it was terrible. I didn’t even want to use it because it got so many words wrong and you had to train it for like 4 hours. But now, you just have to train it for 20 minutes and even when I mumble it gets the words right.” Using the example of voice to text speech recognition software, this user was able to compare current BCI accuracy and efficiency with the level of functioning that this specific program provided ten years ago. Through this comparison, multiple users expressed the belief that, like speech to text technology, BCI has the potential to become a

convenient and beneficial assistive technology option in the near future with the help of research and advancement.

Finally, while still comparing BCI to existing technology, when asked if participants would advocate for BCI as a future assistive technology option, users and caregivers agreed that, with improvements, they would advocate for BCI as an “alternative” to other existing assistive technology offerings. This response aligned with the fact that both user and caregiver responses for advocating for BCI on a regular basis increased over the course of the three sessions (see Figure 3). Through the qualification that they would advocate for BCI as an alternative option to existing assistive technology offerings, participants clarified that each individual’s situation is different and, for this reason, different forms of AT are beneficial for different situations.

BCI and its Relationship to Independence

The final theme that emerged represented the shared user and caregiver experience of setting up and using the BCI system, and the concept of independence. Throughout the discussion, this theme continued to be brought up as the core reason for why BCI has the potential to one day be a useful system to help improve the user’s quality of life.

When discussing the participants’ perspectives and ideas for future uses of BCI systems, a variety of examples of real-life applications surfaced, which participants believed would be helpful in improving their lives. When digging deeper into these ideas, during the focus group data analysis, the root behind all of these suggestions was based in BCI’s ability to improve the user’s independence. When directly asked about how BCI could help to improve participants’ lives or the lives of other persons with disabilities, one user responded “I would say independence is huge. Like, just being able to turn on your own lights, just to be able to walk in your own door... that is huge. Not having someone have to take care of you all the time.” A

caregiver contributed “It would just be great to be able to have real independence in your life and not have to depend on people.” Another user added “I mean anything that is going to increase independent living is going to increase quality of life.”

When participants were asked if they could choose one thing that BCI could do for them, the majority of participants mentioned aspects of the environment that they would like to be able to control, such as changing the channel on a television, adjusting the temperature on the thermostat, or being able to open a door. One participant mentioned “big stuff like being able to turn on and off a shower. No one can think of that,” implicating that other current assistive technology options do not allow him to control the faucet in his shower. When delving deeper into that answer the user explained he chose that option because “If it is about independence, that is another level,” indicating that if BCI were able to help him do this, it would increase his independence more than other existing technologies because it would allow him to take a shower without the assistance of a caregiver. When responding to this same question, another user simply answered “independence” for the one thing that he wanted BCI to be able to do for him. Based on these comments, it is possible that the connection that users viewed between independence and environmental manipulation could be one reason why EADL was the most commonly chosen answer for users when asked where they wanted BCI to improve their current participation (See Figures 5 and 6).

In addition to the concept of independence, a related concept of autonomy was referenced, based on an experience that one user and his caregiver had while he was in a coma. His caregiver explained “(user) does not need [BCI] as much now, but there was a time when it would have been terrific if he could have told us more about what he needed.” She spoke about the potential benefits of BCI allowing the user to speak in full sentences while in the hospital

such as “I want real food,” “I want to sit up more,” or “get me out of this room!” She believed that if the user had been able to express himself in this way and had been more in control of his situation, “it would have helped him heal faster.”

DISCUSSION

At present, despite evidence suggesting that BCI can be used effectively by persons with motor disabilities in the home and despite research showing that this population has expressed strong interest in this technology, BCI is currently not being used by this population on a regular basis. The purpose of this study was to address this gap through assessing both the user and caregiver experience of using BCI technology in the home. According to Phillips and Zhao (1993), non-use or abandonment of assistive technologies occurs when users are not involved in the development, selection, and integration of these technologies into their lives. Through speaking directly to target populations: persons with motor disabilities and their caregivers, and through implementing the technology in the actual environment where BCI will one day be used, this study set out to understand the priorities and perspectives of these groups to find out what needs to be changed to make this technology more usable in daily life.

Although similar studies have already been conducted, up to this point in time, research focusing on gaining the perspective of target populations has been missing at least one important element. For example, Peters et al., (2015) addressed the user perspective through gaining the experience of BCI users with a wide variety of motor disabilities using surveys and interviews to collect data from both novice and expert BCI users. Because of this participant pool, although this study provided useful evidence about the experience of using BCI, no data was generated about the experience of caregivers. On the other end, both Liberati et al., (2015) and Blain Moraes et al., (2012) collected data from both caregivers and users, but because both studies focused on participants with ALS alone, the results cannot be generalized persons with other types of motor disabilities or their caregivers. In addition, in the case of Liberati et al., (2015),

none of the participants had experienced BCI technology first hand and in the case of Blain-Moraes et al., (2012), none of the participants had experienced the technology in their own home environment. Based on this information, the present study is unique in that it included all required elements: it incorporated both users and caregivers, all participants in the focus group had experienced BCI first hand in their home environment, and persons with various types of motor disabilities were included in the study. In addition, this study was the first to incorporate both quantitative and qualitative research methods to look at differences between the opinions of caregivers and users and to study changes in participant opinions over time.

From the quantitative aspects of the study, although analysis of questionnaire responses did not yield any significant relationships, patterns found in the data can be used to hypothesize valuable findings about both the user and caregiver experience of using BCI technology. In addition, findings from these patterns can help to better explain certain aspects of the focus group results. The first relationship that was found to approach significance was the change in all participants' ratings for "ease of use" from session 1 to session 3. While the mean response for all participants after session one was 8.22 out of 10, by the third session, this number had decreased to 6.8 indicating that, counterintuitively, participants rated the system as more difficult to use after experiencing the technology multiple times. While there are a variety of possible explanations for this change, based on content of the focus group discussion, one major reason for this decline could be based on the accuracy of the system. Although users and caregivers both expressed that set-up of the system became easier over time with practice, according to the focus group discussion, because of unavoidable factors such as fatigue, frustration, and distractions in the environment, users continued to experience difficulty with accuracy despite the benefit of

practice. Based on this concept, it is possible that users became frustrated after expecting to improve over time.

The second quantitative relationship that was found to approach significance was the difference between user and caregiver ratings for the likelihood of using or advocating for the use of BCI on a regular basis. While after session three, the mean user rating for the likelihood of wanting to use BCI on a regular basis was a 4.6 out of 10, the mean caregiver rating for the likelihood of advocating for the use of BCI on a regular basis was 8.8. Based on this difference, it appears that caregivers, as a whole, were more likely to support the use of BCI than those who actually experienced the system first hand. One possible explanation for this discrepancy could again be related to the accuracy of the BCI system. While the caregiver experience of setting up the system improved over time, the user experience of using the system was rated to become more difficult over time. One promising finding, however, is that although user ratings for likelihood of using the system on a regular basis were lower than those of the caregivers, user ratings were found to increase over the course of the three sessions.

For the questions relating to participants' views on where BCI could help improve participation, one interesting finding was again relating to the discrepancy between user and caregiver responses (see Figures 5 and 6). For both questions: "In which area of your life would you use this version of BCI technology to increase your current participation?" and "In which area of your life would you want BCI technology to increase your current participation?" the most commonly selected area for users was EADL while caregivers most commonly selected verbal or written communication. One possible reason for this difference could be the fact that users, after experiencing the system first hand, were better able to understand how the two BCI approaches could be translated into functional daily applications while caregivers might have

taken a more literal interpretation due to the fact that two of the three sessions focused on a spelling task. During the focus group, possibly as a result of there being more users present, EADL applications of BCI heavily dominated the discussion. After hearing more about user ideas, caregivers seemed to become more enthusiastic about EADL applications over time.

For the qualitative aspects of the study, in addition to confirming findings of past research, a variety of new concepts were introduced that can be helpful in informing future research and development in BCI. For the response to research question 1, a variety of barriers that have been mentioned in previous BCI studies were confirmed including decreased comfort, limited mobility, decreased accuracy, and complicated, lengthy set-up (Blain-Moraes et al., 2012; Peters et al., 2015). Because these findings align with the findings of research conducted as early as 2012, one important thing that this could tell us is that over the course of four years, little has changed when it comes to BCI usability. Other novel concepts gained from this discussion include the fact that comfort and limited mobility were identified as the most significant barriers and that common characteristics of a variety of difference motor conditions were interpreted to cause decreased accuracy of the system. Although the effect of characteristics such as low vision and fatigue have been referenced in past research, this is the first time that the concept of frustration as a result of a motor condition has been referenced as an additional characteristic affecting BCI use for this population (Blain-Moraes et al., 2012; McCane et al., 2014). Because this is the first study to specifically address user and caregiver opinions about barriers to BCI use in the home, the issues of distractions, 60hz interference, and the number of people required to set up the system are previously unaddressed issues that should be taken into consideration in future BCI development.

For the answer to research question 2, caregiver feedback about improved ease of set-up with practice is promising for BCI use in the home and these comments are supported by questionnaire data which showed that caregiver ratings for ease of set-up increased over time. Feedback from users and caregivers that the ability to customize aspects of the software to the user is also useful for future BCI developers to take into consideration. For research question 3, a variety of concepts from past research were confirmed including the desire to reduce the number of wires and eliminate the use of gel in the EEG cap (Peters et al., 2015; Blain-Moraes et al., 2012). Changing the cap to be less noticeable in social situations is also a concept that has been explored in past qualitative research along with the need to connect BCI system to useful outputs such as a cell phone or computer to enable texting or emailing (Blain-Moraes et al., 2012). These concepts support the findings of Blain-Moraes et al., (2012) who reported that relational factors, or the relationship that BCI systems have to existing technology, the physical body of users, and the user's social connections are important to users and vital factors that should be taken into consideration in BCI development.

In terms of emergent themes, the link between BCI and independence is a concept that has been explored in past research and remains a vital lifeline behind participants' support for BCI. Participant opinions about the role that BCI can play in facilitating independence and the impact that this can have on quality of life support the findings of Blain-Moraes et al., (2012) who reported that the ability to maintain autonomy and independence via actions such as controlling the environment and changing the television channel, was described as important for maintaining a sense of agency for BCI users with ALS. In both this and the present study, independence and autonomy served as the guiding force behind participants' positive feelings about BCI along with their hopes and dreams for future BCI systems.

The two remaining emergent themes are novel and have not been referenced specifically in past research. The theme of BCI and its relationship to existing technology is important for a variety of reasons. In this study, these relationships were valuable because they helped participants to imagine the spaces that BCI can one day inhabit, fueling ideas for potential future applications of BCI. However, in addition to helping expand participants' imaginations, these comparisons also have the potential to inform BCI developers about existing technologies that these populations currently benefit from. Through having a better understanding of how and why these technologies are beneficial, developers can potentially use this information to improve and refine the capabilities of BCI. For example, through learning about the experience of the user who believed that existing technology such as voice recognition software helps improve his quality of life by giving him control of his environment through his voice, it is possible to see how developing a BCI system with similar capacities could greatly benefit someone who is not able to speak. In addition, user's comparisons to the capabilities of voice-to-text speech recognition software of ten years ago can give hope to developers and users of BCI that, although current BCI systems are far from perfect, it is possible for systems to grow and improve over time.

In addition to comparison to existing technology, the theme of cost-benefit analysis is a valuable concept that can help to shape the way that both developers and researchers can view the usability of a BCI system. Although at present, none of the participants included in the focus group discussion believed that BCI would be a beneficial addition to their life, all participants were able to imagine situations where the benefits of the system could outweigh the challenges. Participants believed that if the need was great enough, the inconvenience of setting up the system would be "worth it." For example, in situations where a BCI user was unable to speak,

because BCI would allow this person to regain the ability to communicate, the benefits of using the system would be much greater than for a user who could already communicate independently; therefore, according to participants, in this situation, the benefits of the current system would outweigh the cost. Using the same concepts, participants believed that if the benefits of the current system were improved or the inconvenience of setting up the system were to decrease, BCI would become a beneficial addition to their life. Although this concept is simple, it is possible that this thought process could be beneficial in BCI development through encouraging developers to place focus on specific populations who would benefit more from BCI. In addition, this idea can help developers to direct their focus toward ways to either increase the benefits of BCI or decrease the inconvenience of using the system to meet the demands of these populations.

IMPLICATIONS FOR OCCUPATIONAL THERAPY

If the opinions of user and caregivers expressed in this study are taken into consideration and implemented into future development of BCI systems, BCI technology will one day be a powerful tool that occupational therapists can use to promote greater engagement in meaningful occupations for persons with motor disabilities. However, in addition to contributing to future development, the results of this research can also help occupational therapists to better understand the personal experience of living with a motor disability or as a caregiver for this population. Important areas that this study can give insight into include:

- Areas of participation where persons with different motor disabilities currently experience difficulty
- Areas of participation that are the most meaningful to this population
- Existing assistive technology options that are beneficial to this population
- Priorities and challenges for caregivers

LIMITATIONS

Although this study provides important information about the opinions and preferences of persons with motor disabilities and their caregivers, a number of factors could limit the generalization of findings to these populations as a whole. One limitation of this study is the small sample size included in the questionnaire administration and focus group discussion. Although participants with a wide variety of diagnoses were included, because only ten individuals' perspectives were ultimately assessed, the views and opinions expressed in this study cannot be assumed to represent those of all persons with motor disabilities or all caregivers for this population. Another limitation of this study is the fact that all participants, though significantly affected by a motor disability, were at moderate to maximum levels of functioning. All participants could speak independently and, with the assistance of caregivers or existing technology, were currently able to complete all necessary activities of daily living and instrumental activities of daily living. Because of this, the opinions of these participants may differ significantly from the perspectives of persons with more severe forms of motor disability such as persons with progressive forms of ALS or MS. Another limitation is based on participants' limited exposure to BCI technology. Because participants in this study were only exposed to BCI on three occasions using a P300 based BCI system and two specific approaches within this system, the opinions about BCI gained from this study might not translate to different BCI systems or more prolonged use of the system in the home.

In addition to these limitations, another factor worth noting was the decision to use a 64 channel BCI system. As briefly explained in the introduction, in this study, both online and offline data analysis was used. For this reason, although 64 channels of data were collected using a 64

channel EEG cap, only eight of these channels were used online. The purpose of this decision was to promote future system improvement through determining if fewer or more channels would provide increased accuracy, and to determine which specific channels would provide the most accuracy. As a result of this decision, the BCI system required significantly more set up than that of an eight channel EEG system. This decision could be considered a limitation because the choice to use a higher channel system could have directly affected the participant experience of setting up, and potentially using the system. Specifically, discussion related to challenges such as the use of too many wires, the complicated nature of the BCI system, the decreased comfort of the system, and the inability to move while using the system could have been directly affected by this decision.

A final limitation to the study is in relation to the administration of user and caregiver questionnaires in the home. Although steps were taken to attempt for the same research team member to administer the same questionnaire to the same participant each visit, because of scheduling limitations, the person administering the questionnaire was not able to remain consistent throughout the visits. In addition, due to spatial limitations in the home, in some cases users and caregivers were unable to be separated during the questionnaire administration, even though when possible, these questionnaires were conducted in separate rooms. Because of this fact and the lack of establishing inter-rater reliability among the researchers, it is possible that the responses to the questionnaires could have been influenced by different administration styles and the presence of the caregiver or user in the room.

CONCLUSION

The results of this study illustrate that while persons with motor disabilities and their caregivers are interested in BCI technology and hopeful for its future, a variety of changes would be required to make the present system a valuable addition to the lives of these ten participants. With that said, participants did express that they believe there are applications where current BCI systems could provide benefit to specific populations where the need for such a system is more acute, such as in situations where a person's condition interferes with their ability to communicate independently. Through minimizing the barriers of BCI use and maximizing its benefits, participants expressed that BCI would become a more usable and practical system for a larger population. This study presents findings that both confirm the results of past BCI research relating to current barriers while also offering new insights into the different experiences of users and caregivers in order to inform future BCI development to be more usable and practical in the home of persons with motor disabilities.

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APPENDIX A

BCI User Experience Questionnaire
Participant Number _____
Trial Number _____

Colorado State University BCI User Experience Questionnaire

Purpose: To gain a greater understanding of the *personal* experience of using brain computer interface (BCI) technology in order to help guide future development to make the technology more accessible, useful, and enjoyable for those who use it.

Brain Computer Interface (BCI) Definition: A system that measures activity in the brain and converts these brain signals into outputs that can be used to change the interaction that the user has with his or her environment (J. Wolpaw; E. Wolpaw, 2012). BCI has notable potential for individuals with motor disabilities to be used as a tool to control locomotion, communication, and improve quality of life through converting brain activity into usable commands for external devices, e.g. to control prosthetic devices, drive a power wheelchair, input keyboard characters for typing, etc. (Bamdad, Zarshenas, & Auais, 2015). Because of these possibilities, future BCI development has the potential to one-day fill in the gaps that exist in the abilities of today's assistive technology options.

1. How would you rate your experience using this technology in terms of ease of set up for the caregiver or user? Please circle one number below.

Extremely Difficult to set up	1	2	3	4	5	6	7	8	9	10	No issues setting up
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COMMENTS:

2. How would you rate your experience using this technology in terms of ease of use? Please circle one number below.

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Extremely difficult to use	1	2	3	4	5	6	7	8	9	10	No issues with use
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COMMENTS:

3. How would you rate your experience using this technology in terms of comfort? Please circle one number below.

Extremely uncomfortable	1	2	3	4	5	6	7	8	9	10	Comfortable
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COMMENTS:

4. How many hours per day do you feel you could use the BCI system comfortably? Please check one box below.

<input type="checkbox"/>	Less than 1 hour	<input type="checkbox"/>	4-5 hours
<input type="checkbox"/>	1-2 hours	<input type="checkbox"/>	Greater than 5 hours
<input type="checkbox"/>	3-4 hours	<input type="checkbox"/>	

COMMENTS:

5. Considering your experience of using the BCI technology in this study, how likely is it that you would want to use this type of assistive technology in your home on a regular basis?
Please circle one number below.

⊕

Not at all likely	1	2	3	4	5	6	7	8	9	10	Definitely Likely
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Why or why not?

4

6. In which area of your life would you use this version of BCI technology to increase your current participation? Please mark the three most important areas. If you use the category "Other" please mark only two other areas.

	Physical Mobility		Verbal or written Communication
	Expression of thoughts/opinions/ideas		Formal education
	Informal learning and personal development		Activities of Daily Living (e.g. dressing, bathing, eating etc.)
	Decision making about my own situation		Relationship with my partner
	Relationship with family, friends		Occupation, employment
	Participation in social life		Comfort (e.g. changing positions, privacy)
	Participation in cultural or political life		Personal safety (e.g. indoor and outdoor monitoring, emergency calls)
	Access to Internet, social media, mass media		Environmental controls (e.g. thermostat, lighting, <u>other appliances</u>)
	Entertainment, gaming		Other:

COMMENTS:

7. In which area of your life would you want BCI technology to increase your current participation? Please mark the three most important areas. If you use the category "Other" please mark only two other areas.



	Physical Mobility		Verbal or written Communication
	Expression of thoughts/opinions/ideas		Formal education
	Informal learning and personal development		Activities of Daily Living (e.g. dressing, bathing, eating etc.)
	Decision making about my own situation		Relationship with my partner
	Relationship with family, friends		Occupation, employment
	Participation in social life		Comfort (e.g. changing positions, privacy)
	Participation in cultural or political life		Personal safety (e.g. indoor and outdoor monitoring, emergency calls)
	Access to Internet, social media, mass media		Environmental controls (e.g. thermostat, lighting, <u>other appliances</u>)
	Entertainment, gaming		Other:

COMMENTS:

8. Do you believe that BCI could play a role in improving your quality of life? Why or why not?

9. Do you believe that BCI could play a role in increasing your independence? Why or why not?

10. What did you like about this technology and why?

11. What did you not like about this BCI technology?
Why?

12. Do you have any suggestions to improve your
experience with BCI technology?

B

13. What would you like researchers and developers of BCI to know and consider as they improve and refine the technology?

14. Would you be interested in participating in a future BCI research project?

APPENDIX B

BCI Caregiver Experience Questionnaire
Participant Number _____
Trial Number _____

Colorado State University

BCI Caregiver Experience Questionnaire

Purpose: To gain a greater understanding of the *personal* experience of using brain computer interface (BCI) technology in order to help guide future development to make the technology more accessible, useful, and enjoyable for potential users and caregivers.

Brain Computer Interface (BCI) Definition: A system that measures activity in the brain and converts these brain signals into outputs that can be used to change the interaction that the user has with his or her environment (J. Wolpaw; E. Wolpaw, 2012). BCI has notable potential for individuals with motor disabilities to be used as a tool to control locomotion, communication, and improve quality of life through converting brain activity into usable commands for external devices, e.g. to control prosthetic devices, drive a power wheelchair, input keyboard characters for typing, etc. (Bamdad, Zarshenas, & Auais, 2015). Because of these possibilities, future BCI development has the potential to one-day fill in the gaps that exist in the abilities of today's assistive technology options.

1. As a caregiver, how would you rate your experience using this technology in terms of ease of set up? Please circle one number below.

Extremely Difficult to set up	1	2	3	4	5	6	7	8	9	10	No issues setting up
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COMMENTS:

2. As a caregiver, how would you rate your experience using this technology in terms of ease of use for the person you are providing care for? Please select one number below.

Extremely difficult to use	1	2	3	4	5	6	7	8	9	10	No issues with use
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COMMENTS:

3. During this BCI session, what percent of the process were you involved in as a caregiver?

Not Involved	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
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COMMENTS:

4. Considering your experience of using the BCI technology in this study, how likely is it that you would advocate for the use this type of assistive technology on a regular basis?

Not at all likely	1	2	3	4	5	6	7	8	9	10	Definitely Likely
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COMMENTS:

5. In which area of life would do you believe this version of BCI technology could help increase the user's current participation? Please mark the three most important areas. If you use the category "Other" please mark only two other areas.

	Physical Mobility		Verbal or written Communication
	Expression of thoughts/opinions/ideas		Formal education
	Informal learning and personal development		Activities of Daily Living (e.g. dressing, bathing, eating etc.)
	Decision making about personal situation		Relationship with partner
	Relationship with family, friends		Occupation, employment
	Participation in social life		Comfort (e.g. changing positions, privacy)
	Participation in cultural or political life		Personal safety (e.g. indoor and outdoor monitoring, emergency calls)
	Access to Internet, social media, mass media		Environmental controls (e.g. thermostat, lighting, <u>other appliances</u>)
	Entertainment, gaming		Other:

COMMENTS:

6. In which area of life do you believe future BCI technology has potential to help increase the user's current participation?
 Please mark the three most important areas. If you use the category "Other" please mark only two other areas.

	Physical Mobility		Verbal or written Communication
	Expression of thoughts/opinions/ideas		Formal education
	Informal learning and personal development		Activities of Daily Living (e.g. dressing, bathing, eating etc.)
	Decision making about personal situation		Relationship with partner
	Relationship with family, friends		Occupation, employment
	Participation in social life		Comfort (e.g. changing positions, privacy)
	Participation in cultural or political life		Personal safety (e.g. indoor and outdoor monitoring, emergency calls)
	Access to Internet, social media, mass media		Environmental controls (e.g. thermostat, lighting, <u>other appliances</u>)
	Entertainment, gaming		Other:

COMMENTS:

7. Do you believe that BCI could play a role in improving **your** quality of life as a caregiver? Why or why not?

8. What did you like about this technology? Why?

9. What did you not like about this BCI technology? Why?

10. Do you have any suggestions to improve your experience with BCI technology or the experience of the potential user you provide care for?

11. What would you like researchers and developers of BCI to know and consider as they improve and refine the technology?

12. Would you be interested in participating in a future BCI research project?